

ABUEL

Study protocol

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Principal investigator: Joaquim Soares

Study protocol: Jutta Lindert, Martha Csöff

1. Abstract

Elder abuse and its health/well-being outcomes are increasingly a source of great concern world-wide, but there is relatively little concrete information about these subjects. Some available findings suggest that the abuse of elder persons is relatively common in Europe. However, these findings present various limitations. For example, elder abuse prevalence/incidence data are shaky and inconsistent, the data are in many cases based on care-givers reports rather than on reports from the elder's themselves, and the assessment of elder abuse has often as starting point a broad range of blurred conceptualizations.

The lack of reliable data about elder abuse and its health/well-being effects are evident in the EU, not least in the states participating in the project. For example, not only there is a lack of reliable data about the prevalence and effects of elder abuse, but also on availability and effectiveness of procedures in reporting on elder abuse and neglect as well as on possible prevention and treatment strategies. Furthermore lacking are cross-national data addressing issues of cultural differences, for instance, in the perception of the phenomenon.

There is therefore an enormous need of sound data on the situation of older people with regard to these topics. This will be tackled by the ABUEL project through collecting, among other things, representative and comparable data on the magnitude/characteristics of elder abuse and neglect, its determinants and health/well-being effects in 7 member states. This will allow relying on comparable data to facilitate comparisons between countries, thus, contributing to the planning and/or improvement of policies related to the care of the abused older women/men namely in terms of for instance health services provision, reporting strategies and prevention programmes.

2. Background and Significance

The world is growing older. Estimations indicate that by the year 2025 the numbers of persons in the world aged 60 years and older will more than double, from 542 million in 1995 to about 1.2 billion. A similar trend is expected for the over 65 year old population in the EU, which between 2000 and 2030 will increase from 15.7% to over 24.7% of the total population. This demographic development is pushing in many countries for structural changes in the organisation of current welfare systems, especially in terms of pension schemes and provision of health and long-term care. If these changes do not take place or occur too slowly, the possibility to provide appropriate emotional, social, health and material support to older people becomes difficult, causing marked inequalities between and within countries in terms of, for instance, financial resources, employment opportunities, pension and access to good services and health care. Older age is also often associated with chronic, largely incurable and disabling diseases, such as for instance diabetes, dementia or osteoporosis. Overall, this makes the elderly vulnerable to a range of problems, including neglect, abuse and financial as well as psychosocial difficulties.

Abuse and health/well-being effects among elder

Elder abuse and its consequences on health/well-being are nowadays public health/criminal justice problems in the EU. Over the years the European Union and its organisms have passed a number of policies and supported various initiatives/projects concerning for example older people's quality of life, well-being, health and care management, experiences of abuse/neglect and strategies to improve health (e.g. Healthy Ageing; Violence and Grave Neglected of the Elderly, InMoSion, Netcarity, CAALYX). Many of the projects pertain to for instance reviews of data, recommendations for an integrated EU approach to ageing and health, and focus groups where participants are asked about the roles of the elderly and their views on what elder abuse is, and how often it occurs etc. Indeed, there is surprisingly relatively little concrete, reliable information about elder abuse and its health/well-being outcomes.

However, some data do exist about elder abuse and its health/well-being effects, albeit mostly from North America. These data suggest that elder abuse is relatively common (an overall abuse rate of up to 36 per 1000 elderly persons has been reported) and connected with a high risk for ailments such as depression, anxiety, injuries and physical symptoms (e.g. heart), which may confer an additional risk of death. For example, in an American study about mortality rates among 2812 older people, it was found that 13 years after the study began 40% of those originally reporting no abuse/neglect were still alive, contrasted to 9% of those who had been abused/neglected.

3. Study Aims

ABUEL aims to examine:

1. Demographic/socio-economic differences between abused and non-abused women/men aged 60-84 years (this is covered).
2. Physical/mental health differences between abused and non-abused women/men aged 60-84 years (e.g. physical symptoms, physical problems, depression etc).
3. Medication and health care service use, functional status and life-style differences between abused and non-abused women/men aged 60-84 years (except for medication this covered).
4. Quality of life and social support differences between abused and non-abused women/men aged 60-84 years and to
5. The prevalence and the characteristics of abuse among women/men aged 60-84 years; and to
6. Identify and quantify determinants of abuse, physical and mental health, quality of life and social support among women/men aged 60-84 years, while controlling for potential confounders (e.g. socio-economics).

4. Administrative Organization of ABUEL

The ABUEL research groups consist of institutions in 7 European countries (table 1). The project co-ordinator of the ABUEL research group is Prof. Joaquim Soares from the Karolinska Institute in Sweden.

Table 1: Name of the participating institution, name of the partner, work packages (WP)

Name of participating institutions	Name of partners	Work packages
Karolinska Institute Department of Public Health Sciences, Division of Social Medicine, Norrbacka, SE-171 76 Stockholm, Sweden	Joaquim Soares, project co-ordinator	WP 1, 2, 3, 6
Protestant University of Applied Sciences Ludwigsburg Department of Public Health Sciences, Paulusweg 6, D-71638 Ludwigsburg, Germany	Jutta Lindert	WP 4, 6
University of Granada Faculty of Medicine at University of Granada Departmental Section of Psychiatry and Psychological Medicine, Avenida de Madrid, 11, 18071 Granada, Spain	Francisco Torres-González	WP 6, 8
Italian National Research Centre on Ageing Department of Gerontological Research, Unit of Health Economics, Via Santa Margherita, 5 60124 Ancona, Italy	Giovanni Lamura, M. Gabriella Melchiorre, Sabrina Quattrini	WP 7, 6
National School of Public Health Department of Sociology, 196 Alexandras ave. Athens 115 21, Greece	Elisabeth Ioannidi-Kapolou	WP 6
Kaunas University of Medicine Department of Health Management, A. Mickeviciaus st. 9, LT-44307 Kaunas, Lithuania	Mindaugas Stankunas	WP 5, 6
University of Porto Department of Hygiene and Epidemiology Alameda Prof. Hernâni Monteiro, 4200-319 Porto, Portugal	Henrique Barros, Sonia Fereirra-Dias	WP 6

5. Study Design

Design

ABUEL is a multi-centre cross-sectional study.

Study endpoints

Prevalence of violence/abuse/neglect in the 7 ABUEL countries.

Study population

The study population is selected with the following inclusion- and exclusion criteria:

Inclusion criteria:

- people between 60 and 84
- legal status: documented
- people living in the community or in sheltered houses.

Exclusion criteria:

- people living in homes for the elderly
- people with possible dementia or severe cognitive impairments (assessed with the Mini-Cog. or with the MMSE).

Sample size:

Sample size determination and power analyses are calculated based on the data provided by each centre.

6. Study Procedures

Preparation of data collection (wp 4)

The preparation of data collection is planned by the partner in Germany. It will draw on existing studies and first summarise instruments which are used to assess violence, abuse, neglect, and mental health among people elder than 60 years in a matrix. Following that the ABUEL-questionnaire will be developed. The questionnaire will have two parts: an obligatory and an optional part. The obligatory part consists of four parts a) screening of mental health status, b) general information, c) mental health, d) violence and neglect, and an optional part. The optional part consists of two parts: a) data on household-income, b) traumatic life events, and c) symptoms of posttraumatic stress disorder.

Compulsory part

a) **Screening** of mental health status

Cognitive functioning will be screened with the Mini-Cog or with the MMSE, which allows detecting cognitively impaired people. Cognitively impaired people will be excluded from the survey.

b) The **general information** will be about socioeconomic status of the elderly, number and characteristics of household members, availability of services.

Specifically, questions will assess:

- typical characteristics in terms of gender, age, country of birth, length of stay in the host country, and command of language
- socioeconomic status (education, professional background)
- availability of care services

c) **Specific information** on Health and Mental Health will be elicited in questions used in other studies.

- lifestyle variables (drinking and smoking patterns)
- pain and physical health
- quality of life
- social support
- symptoms of depression.

d) The fourth part will **assess the dependent variables violence, abuse and neglect** among the elderly. The items are the same like in the UK study to ensure comparability of results.

Translation/back translation guidelines / interview guidelines (wp 5)

Translation/back translation guidelines

The responsible partner of this WP (Lithuania) will provide guidelines for the translation and back translation of the ABUEL questionnaire.

Interview guidelines

Each centre will conduct interviewer training and will provide an interviewer manual for training of interviewers in the respective national languages. Spain will provide written instructions concerning how to deal in cases of victimization and neglect. Germany will design a control chart to monitor the interviews (table 2)

Table 2: Timescale preparation of data collection (wp 4 and wp 5)

Due	Task	Partner responsible	country
End of June 2008	Summary of existing studies	Germany	
June to July 2008	Matrix of instruments	Germany	
July to Sept. 2008	Development of the ABUEL questionnaire	Germany	
September 2008	Circulation of questionnaire to all partners; answers are sent to the leading partner in Germany	Germany	
9 th October 2008	Project meeting in Ancona: agreement on the ABUEL questionnaire	Italy	
24 th October 2008	Checklist for cultural translation and adaptation	Lithuania	
24 th October	Questionnaire ready for piloting	Germany	
31 st October 2008	Draft of Study protocol ready to circulate among ABUEL partners	Germany	
31 st October 2008	Draft of data protocol for data pooling ready to circulate among partners	Italy	
October to Nov. 2008	Translation and finalization of the national questionnaires in the participating countries	All	
10 th November 2008	Ethical application sent to the respective national boards	All	
15 th November 2008	Consent and respondent letters circulated to all partners	Germany	
10 th November to end of December	Selection of interviewers	All	
16 th November 2008	Back translation finished in all countries	All	
17 th -24 th November 2008	Piloting of the preliminary version of the ABUEL questionnaire (at least four interviews in each country) starts	All	
30 th November 2008	Comments to the German team as regards the questionnaire and the consent and information letter	All	
	Comments to the Lithuanian team as regards guidelines for translation and back-translation	All	
22 nd December 2008	Final versions of the questionnaire and of the study protocol circulated to partners	Germany	

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14 th January	Printing of the questionnaires	All
14 th January	Training of interviewers	All
End of Feb. 2009	Findings written up in the first report	Sweden
March 2009	Written instructions about how to deal with victimization and neglect	Spain
March 2009	Creation of a tick-sheet with several possible reasons on why the interview could not be conducted	Germany
March 2009	Provision of instructions concerning data ownership and publications	Spain, with support of Germany and Italy
March 2009	Guidelines for interviewers, administration, ethical behaviour	Portugal, Germany

Preparing of data input and pooling of national data (wp 7)

The responsible partner of this WP (Italy) will provide a data input matrix latest at the end of January 2009, where all variables corresponding to all questions included in the questionnaire will be listed and coded. A coding manual will be provided together with the SPSS matrix, where variable names, widths, order, type and value labels as stated in the SPSS matrix will be reported, in order to facilitate the data entry process.

The involvement of other partners in this WP will consist in the use of the SPSS matrix to enter the collected data or, for those who should choose another package for data entry (e.g. Access or Epidata), to send their data to the responsible partner. The characteristics of the variables as defined both in the SPSS matrix and in the coding manual must not be changed by any of the national teams, in order to avoid errors in the merging of the national data bases into the 7-country data base. All additional variables for country specific information that each national team may wish to add to the questionnaire, must be entered in a different dataset that must not be sent for merging, using the same id-code for matching the obtained data. After cleaning of the national data, the national data sets will be sent to Italy for merging the national data sets. In order to obtain a standardized 7-country database, before sending their data to the responsible team, each partner will need to:

- 1) transform their data from other packages (Access, Excel, etc.) into SPSS;
- 2) verify that the data are in the same format as stated in the SPSS matrix (e.g. name of variables, order, width, etc.).

The final pooled data set is then returned to each national team, who will be able to start national data analysis, as well as to WP8 leader (Spain) for European data analyses (table 3).

Table 3: Time scale for preparing of data input and data pooling (wp 7)

Due	Task	Partner responsible	country
22 nd December 2008	Draft of data input protocol circulated to all partners	Italy	
22 nd December 2008	Draft of coding manual of questionnaire	Italy	
15 th January	Feed back of all partners on the data input protocol and on the manual	All	
30 th January	Data input protocol and manual of data protocol ready	Italy	
2 nd February	Training of data entry and start of data entry	All	
Porto/Lisbon meeting	Discussion and agreement of problems emerging by entering first data (about 10 questionnaires); agreement on data cleaning guidelines	All	
30 th June	Data collection ends	All	
15 th July	Data entry ends	All	
31 st July	Partially cleaned national datasets (e.g. cleaning of outliers) sent to Italy	All	
14 th August	The national data sets are merged by Italy and feedback is given to the national teams for completing national data cleaning	All	
31 st August	Completely cleaned national datasets are sent to Italy	All	
30 th September	Final data pooling/merging and data cleaning at EU level	Italy	
30 th September	EU dataset sent to all partners	Italy	

Data collection (wp 6)

Primary data collection through interviews with elderly in the general population will be conducted in each of the ABUEL countries. The utmost attention will be given to that the interviews are conducted without the interference of third parties. The data collection will be co-ordinated by the co-ordinating centre in Sweden with support of the partner in Germany. In each country a major city will be used for primary data collection. In these selected cities – if possible - the population registers will be contacted and addresses of people between 60 and 84 years will be randomly

selected. In those countries where non population registers are available (e.g. Greece) the random route method will be used for data collection. The selection and recruitment process will be precisely documented in each country. Interviewees will be approached and asked for participation as well as written informed consent will be applied if and as required in the given country. The co-ordinating centre will provide a letter explaining the nature of the study to potential participants. A plan how to intervene when suspected cases of abuse and/or neglect are detected will be circulated among partners. A data matrix in SPSS (16.0) will be generated for data input in Italy.

7. Data analysis (wp 8)

Before all national data are jointly analysed, the national data obtained by the interviews from January 2009 – June 2008 will be pooled by the partner in Italy. Data analysis and processing will be conducted mainly by the project partner in Spain, supported by the partners in Sweden and in Germany. First, data will be described. Secondly, factors associated with elder abuse will be analysed in bivariate analysis. Finally, *multivariate methods* will be applied (e.g. logistic regression analyses and multi-level analyses) to analyse the data in a comprehensive way.

Table 4: Timescale data analysis

Due	Task	Partner responsible	country
October 2009	Project meeting in Granada: discussion about data analysis	Spain	
January to June 2010	Data analyses: descriptive analysis, bivariate and multi-level analyses; examination of different models	Spain	

8. Dissemination of findings

The findings from the interviews will be synthesised stepwise and interpreted to inform recommendations for the *prevention of violence among the elderly*. These recommendations will focus on potential risk factors and will be directly linked to the evidence as provided in the other parts of the project. The co-ordinating centre in Sweden will lead on this.

Table 5: Timescale dissemination

Due	Task	Partner responsible	country
November 2009	First cross-national descriptive synthesis of all results done by Spain	Spain	
December 2009	Analysis of national data. Writing/presenting the findings. Preliminary development of recommendations for prevention of elder abuse, neglect and violence	All All	
March to April 2010	Refinement and wording of recommendations	All	
April 2010	Project meeting in Stockholm with agreement on recommendations	Sweden	
April to May 2010	Final wordings of recommendations	Sweden	
June to July 2010	Completing dissemination activities	Sweden	

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