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TITLE PAGE

Title

Elder mistreatment in a community dwelling population: The Malaysian Elder Mistreatment Project (MAESTRO) cohort study protocol

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Abstract

Introduction: Developing countries are facing a remarkable increase in elderly population. Demographic transition, along with rapid urbanization and changing family structures inevitably expose older adults to risks of abuse. Despite being now recognized as a global health concern, there is still inadequate amount of research into elder abuse and neglect especially in the low and middle income region. The purpose of this paper is to report on the design and methodology of a population-based cohort study on elder mistreatment among the older Malaysian population. The study aims at gathering data and evidence to estimate the prevalence and incidence of elder mistreatment, identify its individual, familial and social determinants, and quantify its health consequences.

Methods: This is a community-based prospective cohort study using randomly selected households from the national census. The study is divided into two phases; phase I: cross-sectional study (baseline), and phase II: a longitudinal follow-up study. The study will employ a multi-stage sampling method to obtain a total of 5000 subjects. Those who agree to participate

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will be enrolled in a cross-sectional assessment and contacted at the 3rd and 5th years following the initial data collection for subsequent follow-ups. Besides prevalence, incidence and risk factors, outcomes of interest include mortality, physical function, mental health, quality of life and health utilization. Statistical analysis will be done using the SPSS version 21.0 software program. Logistic regression models are used to examine the relationship between exposure and outcome variables.

Ethics and dissemination: The study has been approved by the Medical Ethics Committee of the University of Malaya Medical Center and Malaysian National Medical Research Register. Written consent was obtained from all respondents prior to baseline assessment. Findings will be published in appropriate scientific journals and presented at local and international conferences.

Keywords: Elder mistreatment, elder abuse and neglect, longitudinal study, cohort, determinants

Strengths and limitations of this study

Strengths

- Among the first few cohort studies looking into elder abuse and neglect in the region.
- Prospective study design with a long period of follow-up.
- Emphasis not only on epidemiological characteristics but also on determinants at different levels of framework.
- Face-to-face interview, active engagement of local community and personalized contact to ensure high response rate and minimize loss to follow up.
- Study subjects are representative of the rural Malaysian older population as the sampling frame is derived from the national census.

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Limitation

- This study focuses on older adults in the rural area, therefore generalizability of findings to the urban older Malaysians can be an issue.

INTRODUCTION

The publication of "Granny Bashing" in 1975 is generally regarded as the starting point for the systematic research into elder abuse (1, 2). More recently, there has been an expanding movement to improve elderly's rights and their physical and emotional well-being. The World Health Organization has recognized elder mistreatment, also known as elder abuse and neglect (EAN) as a growing challenge to the field of public health, social and criminal justice worldwide. EAN is defined as 'a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an elder person'. This includes detriment to older adults by people they know or with whom they have a relationship, such as the spouse, partner or family member, friend or neighbour, or those on whom they rely for services (3). EAN is broadly categorized into physical, psychological or emotional, financial, sexual and neglect (4).

Research findings in economically developed regions and circumstantial evidence suggest that elder mistreatment is a much more universal phenomenon than what is generally perceived by society. EAN prevalence estimates documented by recent studies varied from as low as 1.1% to

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as high as 44.6% (5). Early studies of elder mistreatment derived from Western countries indicated an association between abuse and gender, socioeconomic status, and ethnicity (6-8). For instance, older women were more likely to experience mistreatment but this differed according to the type of abuse (6). Older adults with cognitive and functional impairment, dementia, disabilities and other chronic health problems are particularly at risk of abuse due to increased dependence on caregivers (9-11). Caregivers' psychiatric disorders, previous history of victimization, poor social support, substance use, high levels of hostility and their dependence on the victim for accommodation and finance also appear to be associated with elder mistreatment (10, 12-14). Others reported shared living arrangement, social isolation, loneliness and caregiver strain as risk factors (12, 15).

The 'mapping' of elder mistreatment occurrences and understanding of its risk factors and health consequences across cultures have been significantly limited by the narrow geographical base of current research, with most being conducted in economically developed countries. This distinct gap in the existing literature is reflected by the paucity of robust studies on EAN in low and middle-income developing nations. The 'identified' risk factors may be less pertinent or not fully applicable to the more conservative Asian cultures, considering the deeply ingrained concepts of family ties and filial piety. Wu and colleagues (2014) found that many Chinese viewed elder mistreatment as non-existent in their community owing to the traditional values and cultural norms which emphasize respect of, and provision of care for parents by adult children. On the contrary, their study findings showed that at least one-third of the interviewed older adults reported experiencing some forms of mistreatment, suggesting the pervasiveness and lack of awareness on EAN in the community (16). Hence, further research to determine the

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extent of elder mistreatment and the universality of its risk factors across different populations is necessary. Empirical data is essential to identify older adults at risk and facilitate the development of community-specific and evidence-based preventive measures.

Malaysia is a multiethnic and multicultural country with a population estimate of 29 million in 2014. According to the World Bank classification, Malaysia is an upper-middle income and developing economy situated in the East Asia and Pacific region (17). Its population consists of mainly ethnic Malays (47%), followed by Chinese (25%), Indians (7%), and indigenous tribal groups (11%). Population projections predict that the number of people aged 60 years and above will form nearly 11 % of the national population by 2020, and this figure will double by 2040 (18). This substantial increase in older populace, along with rapid urbanization and changing family structures will bring about greater challenges to the provision of care for the elderly. Like many Asian countries, most older Malaysians rely heavily on their children for care and financial support. This is especially customary among those living in rural areas where there is inadequate pension and social support system and limited access to medical care, as compared to that enjoyed by their more affluent urban counterparts. The rural-urban migration of youths in search of better job opportunities has also greatly weakened the family's perceived obligation of caring for their elder members. The lack of social safety net coupled with heavy reliance on their children expose the rural older population to a greater likelihood of abuse and exploitation.

A number of countries have enacted statutes for reporting EAN and protection of the elderly. There is no specific legislation to address EAN in Malaysia to date. The provision of the Domestic Violence Act 1994 is relatively non-specific; it covers all family members including

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older adults within a household (19, 20). Official or authenticated data on EAN is also unavailable to gauge the true extent of the problem. While the Malaysian government has demonstrated commitment to protect the rights and welfare of the elderly through a number of initiatives, there remains little information from well-designed community based research into the multiple dimensions of EAN. To address this need, the MAlaysian Elder miSTreatment pROject (MAESTRO) study was designed to estimate the prevalence and incidence of elder mistreatment, describe the characteristics of perpetrators, identify individual, familial, community and social determinants of EAN and assess its health consequences among a representative sample of Malaysian older adults.

Objective of the study and conceptual framework

The overarching aims of the study are to estimate the prevalence and incidence of elder mistreatment, its subtypes and multiple types of mistreatment; to identify the extent to which elder mistreatment is predicted by individual, familial, community and social determinants, and; to determine the consequences of EAN in relation to injuries, physical health and function, mental health, health utilization and mortality.

This project employed a conceptual framework adapted and modified from the World Health Organization. Applying the ecological approach, the framework guided the development of the study design and selection of the range of potential determinants and outcomes of EAN. The central thesis of this framework is the emphasis on the interaction and dynamics of multiple determinants at various ecological levels in which victims and perpetrators are embedded;

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individual, relationship, community and sociocultural. In this study, we examined both the risk factors for, and protective factors against elder mistreatment, along with its outcomes. Figure 1 illustrated the conceptual framework of this study.

[insert Figure 1]

METHODS AND ANALYSIS

Study design

This is a 5-year prospective longitudinal cohort study among community dwelling older adults aged 60 years and older and their caregivers, residing in the district of Kuala Pilah in the state of Negeri Sembilan, Malaysia. It commenced in November 2013 and is currently ongoing. The study will be executed in two phases. Phase I comprises a cross-sectional study and phase II is an open cohort follow-up study across a 5-year period. Participants will be followed up at baseline, 3rd, and 5th year.

Sample selection and Study participants

A two-stage cluster sampling was employed to select study subjects. In the first stage, one representative district, Kuala Pilah was randomly selected from seven districts available in the state of Negeri Sembilan. Negeri Sembilan lies in the central of Peninsular Malaysia, about 100 kilometres away from the capital city, Kuala Lumpur. Its population stands at 1.02 million according to the national census. Compared to other districts, Kuala Pilah has the biggest population of older adults in the state. In the second stage, the Malaysian Department of

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Statistics (DoS) provided a comprehensive sampling frame based on the most recent national census conducted in 2010. Out of 254 enumeration blocks (EBs) within Kuala Pilah, 156 EBs were randomly chosen. Each EB contained a minimum of 15% of older individuals. A computer-generated list of households was then provided, from which 16-20 households were randomly selected from every EB. Maps of the local terrain provided by the DoS were used to locate selected households. The Malaysian Department of Statistics performs the national census every ten years and retains the most comprehensive and up-to-date information on the population demographics (18). This method of complex sampling design ensured adequate coverage of older adults in all parts of the district, yielding a heterogeneous representative sample from the target population.

Respondents were interviewed at home by trained personnel, using a structured questionnaire. An older person and a caregiver limited per household were interviewed. For elder abuse screening questions, participants were interviewed in private without the presence of any family members, while their caregivers were interviewed separately. All interviewers underwent a short training course prior to conducting the survey.

Table 1 presents the eligibility criteria for subject selection in this study. Information gathered from respondents and caregivers included socio-demographic, physical health, medical history, nutrition, psychological status, daily activities, health utilization, and social support and network.

Table 1 Eligibility criteria for the MAESTRO cohort study

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Inclusion criteria	Exclusion criteria
• Older persons aged 60 years or more • Community dwelling elders living at home alone or with family or relatives in the past 12 months • Malaysian nationals • Elders who can communicate with the interviewers	• Elderly residing in long term care institutions • Elders who are unable to communicate with the interviewers, eg. post-stroke, mentally disabled, severe cognitive impairment. • non-resident in the area in the previous 12 months or foreign nationals

Recruitment and follow-up interviews

Follow-up interviews will be performed on the 3rd and 5th year. Participants will be tracked for at least 5 years, or until death. To reduce losses to follow-up, a brief telephone interview will be conducted a year after the follow-up interview to detect any change of residence and health status in the past year. To gain rapport and ensure high response rate from selected subjects, the research team engaged actively with the local community via the Village Safety and Development Committee (VSDC). The VSDC acted as a mediator, assisting researchers in identifying selected house addresses and informing local residents about the possible visit by the research team.

Prior to the commencement of the actual study, a pilot study was conducted to evaluate the feasibility of each instrument on a sample of older adults with a similar age range and geographic area. This exercise contributed to the training of interviewers and development of skills to administer the questionnaire, in order to achieve homogeneity in data collection.

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Sample size calculation

We used the minimum detectable risk ratio required between an outcome and exposure to estimate the sample size. The minimum detectable risk ratio was estimated to be around 2.0 for an outcome (i.e. elder mistreatment) of 10% based on a previous pilot study conducted. Power and a 2-sided alpha were set a priori at 80% and 0.05. Design effect due to complex sampling was estimated to be 2.0. To account for loss to follow-up and mortality in 5 years, the sample size was inflated by 30%. The calculated sample size required was 2470.

Assessment and operational definitions

Elder mistreatment

The primary outcome of interest is elder mistreatment, or elder abuse and neglect (EAN). Older persons refer to those aged 60 and more, in line with the definition established by the United Nations World Assembly on Ageing, Vienna, 1982 and adopted by Malaysia. The definition of elder mistreatment was based on the WHO framework on violence: any abuse and neglect of persons age 60 and older by a caregiver or another person in a relationship involving an expectation of trust. Five types of abuse were measured including physical, sexual, financial, psychological, and neglect. In this study, we identified perpetrators as caregivers or person(s) whom the older adults know, or with whom they have a relationship.

An extensive review of literature was conducted, and we adapted and revised a comprehensive questionnaire developed by Naughton and colleagues (2012) (21). Permission was sought from the national Irish prevalence study research team to use the instrument. In our study however, some items in the questionnaire were modified in order to contextualize EAN within our cultural

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setting. These items were behavior-specific, referring to the types of incidents that respondents may perceive as abusive. Behaviour-specific questions help cue respondents to think of relevant incidents and respond accordingly, thereby increasing the reliability and consistency of the reported incidents. The elderly were asked if they have ever experienced at least one incident of mistreatment, i) since turning 60 years old; or ii) in the past 12 months, by a caregiver or somebody with whom they have a relationship of trust.

The list of acts is presented in Table 2. Physical, sexual and financial abuse are operationalized as any episode of mistreatment reported by older individuals during the reference period and perpetrated by a caregiver or a person in a position of trust. Subsequent questions gathered additional information on the frequency of events, perpetrators' characteristics, perceived seriousness, injuries sustained, respondents' disclosure (or lack of), the person to whom disclosure was made, and ensuing action following disclosure.

Similar to Naughton and colleagues' work and supported by literature elsewhere (6), psychological abuse is defined as 10 or more incidents of mistreatment. When the frequency is less than 10 it is considered to have happened if the episode(s) is perceived by the respondent as having a serious impact. There is no universal or standard definition of neglect. It varies considerably across countries and cultures. When adopting the definition of neglect, we took into consideration the Malaysian context and cultural ethos, in line with the National Policy on Elderly which emphasize older adults' rights to protection, welfare and dignity. In this study, neglect is defined as a caregiver's failure to meet the elder's basic needs such as access to

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medical treatment, adequate nutritional food, clean clothing, proper shelter, and clean and safe living conditions, or the failure of caregiver to provide assistance to the elderly for basic and instrumental activities of daily living. These include feeding, walking, using the toilet, dressing and bathing, preparing food, taking medication and so on.

Table 2: Operational definitions for elder mistreatment

Type of mistreatment	Definition
Physical	▪ Slapped, pushed, grabbed, or shoved ▪ Kicked, bite or hit with a fist or object ▪ Inappropriately restrained in any way, e.g. locked in room/house, tied in a chair, tied on bed, chained elderly ▪ Fed too much medicine or drugs to control ▪ Burned or scalded ▪ Threatened or assaulted with a knife, gun or other weapon
Financial	▪ Stole elderly's money, things, property or documents ▪ Purposely prevented elderly from accessing their money, possessions, property, land or important documents ▪ Manipulated or forced elderly into giving money or hand over property, land, possessions or other important documents ▪ Forced or manipulated elderly into altering their will or any other financial document ▪ Deliberately forge or signed cheques or other financial documents without elderly's permission ▪ Misused the power of attorney given by elderly or forcing or manipulating elderly into giving him/her power of attorney
Sexual	▪ Sexually harassed or talked in a way that made the elderly uncomfortable ▪ Touched or tried to touch in a sexual way against the elderly's will ▪ Forced or attempted to force to have sexual intercourse against the elderly's will
Psychological	▪ Cursed, shouted or insulted ▪ Humiliated, belittled or embarrassed ▪ Repeatedly ignored ▪ Threatened verbally ▪ Prohibited family members, friends or doctor/nurse from visiting or vice versa

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Neglect	▪ Access to medical treatment ▪ Enough nutritional food ▪ Clean clothing, ▪ Adequate shelter, clean and safe living conditions ▪ Failure to provide elderly's need for support for basic activities of daily living when required such as feeding, walking, climbing stairs, going to the toilet, dressing and bathing.

Risk and protective determinants of elder mistreatment

Data will be collected from various sources including self-reports by respondents and their caregivers, and physical and clinical assessment. Table 3 shows the risk and protective determinants of elder mistreatment measured at different levels of the framework.

Table 3. Matrix of determinants and its measurement

DETERMINANTS	MEASUREMENT
INDIVIDUAL (ELDERLY)	
Age	The age will be estimated based on the date of birth as recorded in the Malaysian National Registration Identification Card (NRIC). Where necessary, verification with other documents such as driving license, pension book or other government documents are performed.
Sex	Male or female as recorded in the NRIC.
Ethnicity	Ethnic status will be collected as recorded in the NRIC, mainly classified as Bumiputra Malay, Bumiputra non-Malay, Chinese, Indian or others.
Marital status	Based on current marital status as reported by the elderly, which will be categorized into married, single, divorced or widowed

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Living arrangement	Living arrangement to be classified as own home, or others which includes children's home or relatives' home or other persons
Education	Elderly's level of formal schooling; categorized as none, primary, secondary or higher
Income	Elderly financial status will be measured by asking the amount of funding received every month in Ringgit Malaysia (RM). Various sources of support are recorded either current monthly income if working, monthly pension if pensionable, financial aid received through government, NGOs or official sources or estimated amount received from family members if any.
Current employment status	Elderly will be asked if they are currently employed in any capacity.
Co-morbidities (chronic diseases	Elderly will be asked if they had being diagnosed by physician for any chronic illness, which include high blood pressure, heart problems or blood circulation problems, stroke, joint pains or arthritis, Parkinson's disease, diabetes, breathing problems (asthma, lung infections) and cancer.
Physical disability	The Katz Index of Independence in Activities of Daily Living (Katz ADL), and Lawton Instrumental Activities of Daily Living Scale (Lawton IADL), are used to assess an older adult's ability to independently perform self-care and maintenance. Katz activity of daily living has 6 items scored on a 3-point response scale (independent, some assistance, or dependent). Higher score indicates elderly's independence (22). Lawton IADL has 8 items that assess independent living skills that are considered more complex than basic ADL A summary score ranges from 0 (dependent) to 8 (independent) (23).
Physical function	Two aspects of physical function of the elderly will be measured. i. Walking speed– average of two readings for 2.4m walking test in seconds ii. Muscle strength – average of two readings per hand for grip strength measured by dynamometer in kPa.
Cognitive impairment	The Elderly Cognitive Assessment Questionnaire (ECAQ) is a quantitative assessment of cognitive impairment among elderly people. A score lower than 6 are categorized as being cognitively impaired (24).

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INDIVIDUAL (CAREGIVER)	
Caregiver demographic	Caregiver's age, sex, education, employment and household income level will be collected. Education, employment and income will be used as indicators to determine the socio-economic status of the caregiver.
Caregiver's substance abuse	Two items to measure caregivers' substance use including alcohol and drug problem.
Caregiver's mental illness or aggressive behavior	Elderly will be asked if their caregiver has any form of mental illness or aggressive behavior.
Caregiver caregiving and coping skills	Caregiver reactive assessment (CRA) with 24 items designed to assess specific aspects of the caregiving situation, including both negative and positive dimensions of caregiving reactions (25)
Caregiver's prior history of abuse	Caregiver will be asked if they have experience any form of child abuse or domestic violence in the past.
RELATIONSHIP	
Caregiver-elderly relationship	Quality of the caregiver-care recipient relationship measures the quality of the current relationship in relation to general closeness, communication, similarity of views about life, and degree of getting along. It has four items on a 4-point Likert scale response (26).
Living arrangement	Current living arrangement will be categorized as own home, or others which includes children's home, relative's home or other persons
Caregiver depression	Depression Anxiety Stress scale (DASS) is 21 items self-report scale designed to measure the negative emotional states of depression, anxiety and stress experienced by the caregiver (27)
Caregiver burden	Brief COPE is a brief measure with 28 items assessing caregiver's burden and coping mechanism. Higher scores indicate ineffective coping mechanism (28).
Dependency of elderly or caregiver	Two items that measure elderly's fear of abandonment, loneliness and tolerant towards aggressive behavior.
Religious	Salience in religious commitment scale is used to measure the extent

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commitment	to which elderly and their caregiver consider their religious beliefs to be important both in general and decision making. The scale has only three items on a 4-point Likert-type scale. Total scores range from 3 to 11 (29).
COMMUNITY AND SOCIETAL	
Social support	The Duke Social Support Index (DSSI) has 11 item that measure social support received by the elderly. The higher the score, the greater support perceived by elderly (30)
Social isolation	The Lubben Social Network Scale (LSNS-6) is used to screen for social isolation among community-dwelling older. A score of 11 or less on the LSNS-6 indicate social isolation (31).
Social cohesion	The social cohesion and trust domain from the Collective Efficacy Scale (CES) is utilized. It was a 5-item Likert-type scale asking how strongly they agreed to the statements regarding people around their neighbourhood (32).

Health consequences of elder mistreatment

As delineated by our conceptual framework, consequences of EAN are categorized into quality of life, mental health, physical health/ function and mortality. This study will therefore explore four scopes of outcomes: quality of life (QoL), mortality, morbidity and health utilization. For morbidity, physical function (gait speed) and mental health (depression and sleep disturbance) will be measured, whereas health utilization is represented by hospitalization rate and frequency of health visits.

Quality of Life

The Short Form Health Survey SF-12 is utilized to measure health-related quality of life in this study. The SF-12 has both physical (PCS) and mental component (MCS) summary scales which

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comprise eight concepts: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality (energy/fatigue), social functioning, role limitations due to emotional problems and mental health. Each item has a rating scale of 0 to 4.The Malay version of Short Form Health Survey (SF-12) has been validated (33) and will be used in this study.

Mental Health

Two variables will be measured in this sphere: depression and sleep disturbance. Depression will be assessed using the fifteen-item Geriatric Depression Scale (GDS-15). Respondents will be asked whether they have experienced the symptoms described during the past week using the yes/no format. A score of greater than 6 suggests symptoms of depression. The GDS-15 has been validated among the Malay elderly population and found to be reliable, with Cronbach's alpha = 0.84, test-retest reliability= 0.84 and concurrent validity with the Montgomery–Asberg Depression Rating Scale (Spearman's rho 0.68) (34).

Sleep disturbance is measured by the Pittsburgh Sleep Quality Index (PSQI), a validated nineteen-item questionnaire which is used to study the quality and pattern of sleep among older adults. Seven domains of sleep are captured by this instrument: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications, and daytime dysfunction over the last month. Respondents are asked to rate each of these seven component on a scale of 0 to 3, with 3 reflecting the negative extreme on the Likert Scale. A score of 5 or more indicates 'poor sleep' or sleep disturbance. The PSQI has a Cronbach's alpha of 0.83 for all its seven components, and has been said to show high validity and reliability when used among older adult populations across countries (35).

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Mortality

Data on mortality is obtained by regular contact with respondents' family members and caregivers. Reported deaths will be crosschecked with the National Registration Department database, which provides additional information such as the date and cause of death.

Physical health/ function

Gait speed will be quantified as an indicator of physical function. In gait speed assessment, respondents are asked to walk for 4 meters with or without walking aids, and the time taken is recorded. Each participant undergoes the walking test two times, and the best score (time) is taken. Walking speed has been reported to be a good predictor of adverse outcomes in community-dwelling older people (36) and was associated with survival of older individuals (37).

Hospitalization and health visit

Hospitalization is defined as being admitted at any hospital (public or private) for at least 24 hours in the last 12 months.

Hospitalization and frequency of health visits are determined by two questions:

1) 'In the last 12 months, did you ever visit any of the following health facilities?'

2) 'How many times did you visit?'

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The answer options include 'private clinic,' 'government clinic,' 'social service officer', 'outpatient department at a hospital,' 'emergency department,' and 'admitted for at least 24 hours.' Frequency options are given as 'never', 'once', '2-3 times', '4 times or more', '1-2 times/week' and 'everyday'.

Statistical analysis

Data entry and management will be conducted using the SPSS Version 21.0 software program. Double entry method will be performed using standardized coding and labeling approach. All questionnaires will be checked after the fieldwork by a second person to minimize missing data. Any missing data will be investigated and where possible, the respondent will be contacted via telephone. Information collected will be kept in a locked space to which only designated personnel have access. Secondary data (mortality) will be collected from the national registry.

Data will be presented as mean ± standard deviations, percentages, odds ratios (for cross-sectional analysis) or relative risks (for longitudinal analysis). The prevalence (or incidence) of elder abuse, its subtypes and related factors will be estimated according to age and gender. Outcomes will include quality of life, mortality, physical function (walking speed), mental health (depression and sleep disturbance), and health utilization (hospitalization rate and frequency of health visit). Normality of the data sets will be tested for parametric tests. Student t-test or analysis of variance will be used to compare variables among the different groups for continuous data. For comparison of proportions, chi-square analysis will be performed. To investigate the associations between outcomes and studied parameters, multivariate analysis will be employed.

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Possible confounding factors found in univariate analysis will be adjusted in multivariate analysis.

Complex sampling regression analysis will be performed, taking the sample design into account. This procedure will estimate variances by taking into account the design used to select the sample, which is probability disproportional sample without replacement in this case. P value of less than 0.05 will be considered statistically significant and 95% confidence interval will be reported where appropriate.

At subsequent follow-ups, respondents will be compared to non-respondents with respect to characteristics such as sex, age, educational level and health status to detect any systematic differences between these two groups.

ETHICAL ASPECTS

The study protocol was submitted to and approved by the Medical Ethics Committee of the University of Malaya Medical Center (MEC Ref 902.2) and Malaysian National Medical Research Register (NMRR-12-1444-11726). Written permission from the relevant authorities at the community level was also obtained. Respondents' written, informed consent was undertaken prior to the baseline interview.

All respondents were provided with various hotline numbers to report abuse including hotlines dedicated for domestic violence and child abuse such as Talian Nur 15999, Teledera toll-free

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hotline 1-800-88-3040, and the contact numbers of social workers and counselors available in the district. In the event of disclosure of abuse during the interview, respondents would be advised to discuss strategies to deal with this problem with family members or a trusted person. They would also be referred to the social worker or health officer of the district if circumstances were judged to be life-threatening, or if direct requests were made. Respondents' rights and autonomy were observed during the entire research process.

DISCUSSION

The MAESTRO cohort study aims at estimating the prevalence and incidence of elder abuse, identifying its risk factors and characteristics of perpetrators, and assessing its health consequences among community-dwelling older Malaysians. This study is one of the pioneering prospective cohort studies that explore the issue of elder abuse and neglect in this region, particularly among South East Asian countries.

There are several strengths of this study. First, the prospective study design with a long follow-up period is appropriate to determine causality between predicted outcomes and exposure (abuse and neglect). We focus not only on epidemiological characteristics of elder abuse, but also the relationship between determinants at different levels and elder abuse. This study thus is able to evaluate the impact of social environment and elucidate other risk factors of abuse. Second, we are able to follow-up a group of respondents who report having experienced abuse, and assess a range of outcomes including mortality, morbidity and health utilization. Active recruitment and face-to-face interview ensured a highly personalized contact with respondents to increase the

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response rate and retain participants. Face-to face interview is useful to obtain more accurate information as older respondents who have difficulty understanding can directly ask the interviewers for explanation. Using the census provided by the national Department of Statistics as our sampling frame, the MAESTRO study subjects can be considered representative of the Malaysian rural older population.

One major limitation of this study is the locality in which data was collected. As the focus in on rural community dwelling older adults in the district of Kuala Pilah, generalizability of our study findings to the urban elderly populace could be an issue. Results from this study however will provide robust evidence and re-inforce the need for programmes to raise awareness, and interventions at the appropriate level to address elder abuse and neglect in Malaysia.

Upon completing the baseline assessment, we gathered a number of lessons which would be useful for other researchers when conducting a similar study. Active engagement of the local community is extremely important. In rural areas where the social fabric is largely intact and dynamics of social structure is different from that of the urban community, getting the local leaders or influential figures of the locality into the picture will facilitate rapport building with residents and smoother data collection. It is crucial that the research team listens to the local people's needs and suggestions, understands their cultural norms and expectations, and always attempts to create a win-win situation throughout the research processes. Employing local people as part of the research team can be an effective strategy to win the trust of the local community, as the presence of familiar faces will make the elderly feel 'at home' rather than viewing the researchers as outsiders who should be treated with suspicion. In our case, we got several

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authoritative bodies involved; the local leaders, local police force, local health workers, district office, Ministry of Health, and Ministry of Rural and Regional Development. Engagement of multiple and cross-sectoral partners not only ensures researchers' safety but increases accountability and transparency of the research process.

With regards to a sensitive subject like abuse and neglect, an ethical dilemma might arise as to what is the subsequent action by the interviewer upon identifying abuse victims. Indifference or lack of response by the researcher may create misunderstanding among the local elderly, apart from going against the principles of ethics in research. This points to the need for thorough planning before going onto the ground. Adequate information on the local resources, healthcare and social support system is crucial to identify the channels through which abuse victims can receive help. We collaborated with the local health district office and engaged local health personnel and social workers, in order to facilitate referral of abuse victims for further assessment and assistance. However, being a relatively new issue in the healthcare system, limitations were inevitable: we were uncertain of how fast the referral process worked, and whether follow-up was done accordingly. Lack of expertise was another overwhelming issue. Health workers comprised mainly medical officers with no official training in geriatrics or gerontology. Consequently, the research team in collaboration with the Health State Department provided a series of training on detection and management of EAN for all the district medical officers and nurses working in public health facilities.

Incentives are without doubt an effective retention strategy in a cohort study. We provided both pecuniary and non-pecuniary inducements at different phases of baseline assessment. Our

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observation was that, despite pecuniary incentive being more attractive, it has a number of drawbacks. Collecting data in a rural setting forced our team members to carry huge amount of cash from one place to another, which was highly risky and unfeasible. There were attempts by some respondents to profit from what was offered, thereby creating ill feelings and resentment. Non-monetary incentives in the form of small gifts and souvenirs were found to be more reasonable and practical.

Logistics plays a huge role in determining the flow and success of research processes, mainly data collection. When conducting studies in rural areas of developing countries where the local topography has not been properly mapped out, researchers need to anticipate few issues: the available map may be outdated so locating addresses can be a challenging task. Some areas can be difficult to reach via ordinary transportation, and previous physical construction or infrastructure might have undergone transformation at a speed faster then what those in charge of survey and mapping are able to track. While locating the addresses of study subjects, we encountered difficulties as mentioned above, despite being provided with maps of the neighborhood.

In conclusion, the MAESTRO study is one of the first few cohort studies exploring the issue of elder mistreatment in the South East Asian region. It will greatly contribute to a better understanding of the subject of abuse and neglect among older adults in a middle income and developing country. The lessons we learnt in the initial phase of the study are valuable, and will act as a guide during the next phase.

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COMPETING INTERESTS

No conflict of interest has been declared by the author(s).

AUTHORS' CONTRIBUTION

CWY, NNH, RS, RY, FH, NI, and SK conceived the study design. CWY, NNH, RS and RY prepared and drafted the manuscript. RS, SK, NI, DP, SNA, IAR, ZMA, SO, NCW, TMP, MIA, TNP, KC, PB and AB contributed to the study protocol in their areas of expertise. RS, SK, NI, DP, NCW, SNA, IAR, and ZMA were involved in acquisition of data. CWY and NNH were the principal investigators and led the grant application. All authors approved the final manuscript.

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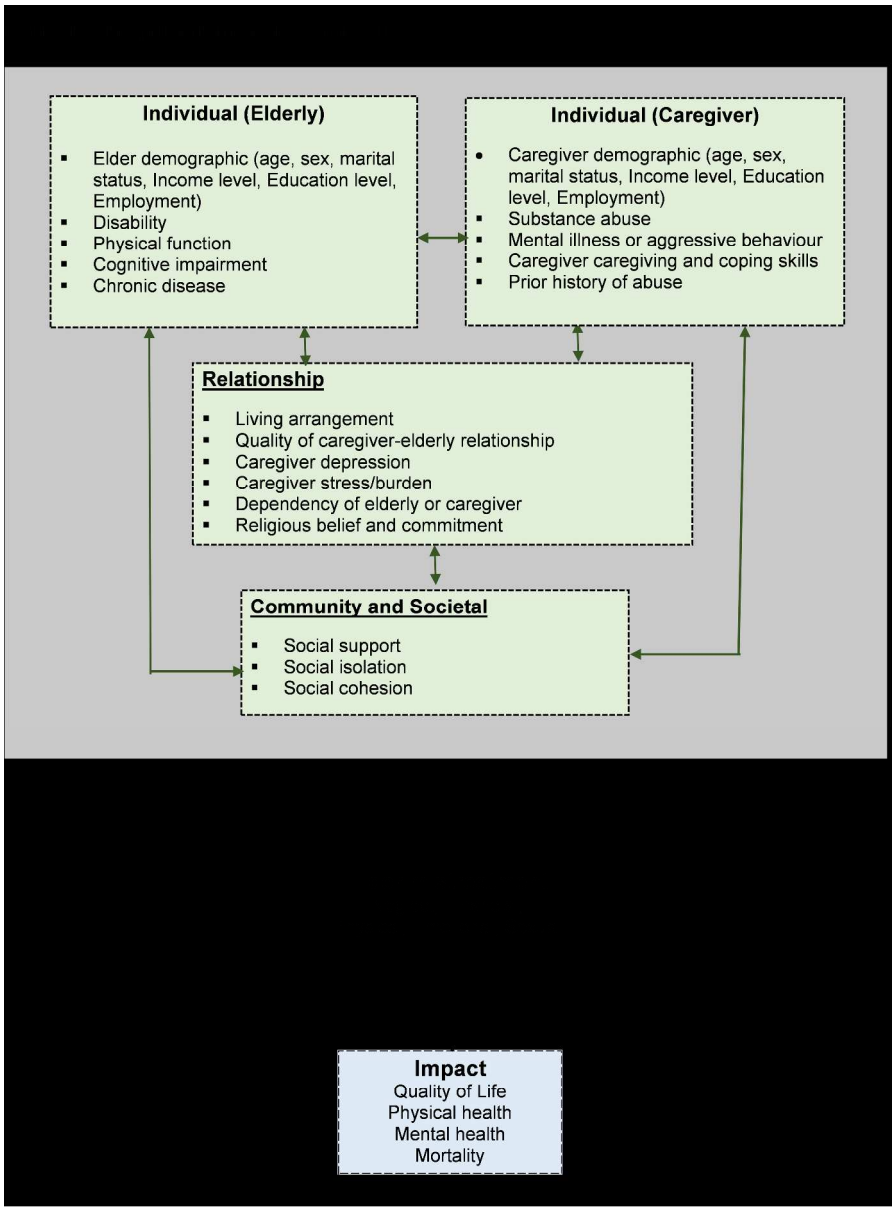

Figure 1: Conceptual framework of this study
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Elder mistreatment in a community dwelling population: the Malaysian Elder Mistreatment Project (MAESTRO) cohort study protocol

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Elder mistreatment in a community dwelling population: The Malaysian Elder Mistreatment Project (MAESTRO) cohort study protocol

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Elder mistreatment in a community dwelling population: The Malaysian Elder Mistreatment Project (MAESTRO) cohort study protocol

CHOO Wan Yuen[1]*, Noran Naqiah HAIRI[1], Rajini SOORYANARAYANA[1], Raudah Mohd YUNUS[1], Farizah Mohd HAIRI[1], Norliana ISMAIL[1], Shathanapriya KANDIBEN[1], Zainudin MOHD ALI[2], Sharifah Nor AHMAD[2], Inayah ABDUL RAZAK[2], Sajaratulnisah OTHMAN[3], TAN Maw Pin[4], Devi PERAMALAH[1], Patricia BROWNELL[5], Awang BULGIBA[1]

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Abstract

Introduction: Despite being now recognized as a global health concern, there is still inadequate amount of research into elder mistreatment especially in the low and middle income region. The purpose of this paper is to report on the design and methodology of a population-based cohort study on elder mistreatment among the older Malaysian population. The study aims at gathering data and evidence to estimate the prevalence and incidence of elder mistreatment, identify its individual, familial and social determinants, and quantify its health consequences.

Methods and analysis: This is a community-based prospective cohort study using randomly selected households from the national census. A multistage sampling method were employed to obtain a total of 2496 subjects living in the rural Kuala Pilah district. The study is divided into two phases; cross-sectional study (baseline), and a longitudinal follow-up study at 3rd and 5th year. Elder mistreatment was measured using instrument derived upon previous literature and

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modified Conflict Tactic Scales. Outcomes of elder mistreatment include mortality, physical function, mental health, quality of life and health utilization. Logistic regression models are used to examine the relationship between risk factors and abuse estimates. Cox proportional hazard regression will be used to estimate risk of mortality associated with abuse. Association annual rate of hospitalization and health visit frequency and reporting of abuse will be estimated using Poisson regression.

Ethics and dissemination: The study has been approved by the Medical Ethics Committee of the University of Malaya Medical Center (MEC Ref 902.2) and Malaysian National Medical Research Register (NMRR-12-1444-11726). Written consent was obtained from all respondents prior to baseline assessment and subsequent follow up. Findings will be disseminated to local stakeholders via forums with community leaders, health and social welfare departments; and published in appropriate scientific journals and presented at conferences.

Keywords: Elder abuse, elder neglect, Elder mistreatment, longitudinal study, cohort

Strengths and limitations of this study

- This study is among the first few cohort studies investigating into elder mistreatment in the South East Asian region.
- It has a prospective study design with a long period of follow-up, with emphasis not only on epidemiological characteristics of elder mistreatment but also on determinants at different levels of framework and measuring consequences of abuse.

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- The study subjects are representative of the rural Malaysian older population as the sampling frame is derived from the national census.
- Face-to-face interview, active engagement of local community and personalized contact to ensure high response rate.
- Given the study focuses on older adults in the rural area, therefore generalizability of findings to the urban older Malaysians can be an issue.
- Exclusion of group most at risk of elder mistreatment, in particularly older adults with dementia, severe cognitive impairment, and residing in long term care institutions may potentially underreport the abuse estimates.

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INTRODUCTION

The publication of "Granny Bashing" in 1975 is generally regarded as the starting point for the systematic research into elder abuse [1,2]. More recently, there has been an expanding movement to improve elderly's rights and their physical and emotional well-being. The World Health Organization has recognized elder mistreatment (or known as elder abuse and neglect) as a growing challenge to the field of public health, social and criminal justice worldwide. Elder mistreatment is defined as 'a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an elder person'. This includes detriment to older adults by people they know or with whom they have a relationship, such as the spouse, partner or family member, friend or neighbour, or those on whom they rely for services [3]. Elder mistreatment is broadly categorized into physical, psychological or emotional, financial, sexual and neglect [4].

Research findings in economically developed regions and circumstantial evidence suggest that elder mistreatment is a much more universal phenomenon than what is generally perceived by society. Elder mistreatment prevalence estimates documented by recent studies varied from as low as 1.1% to as high as 44.6% [5], while Cooper and colleagues in an earlier review found that older population studies generated a prevalence estimate of between 3.2-27.5%. Dependent or vulnerable older people are at higher risk of abuse with nearly a quarter of them reported psychological abuse and a fifth reported neglect [6]. Early studies of elder mistreatment derived from Western countries indicated an association between abuse and gender, socioeconomic status, and ethnicity [7-9]. For instance, older women were more likely to experience abuse but this differed according to the type of abuse [7]. Older adults with cognitive and functional impairment,

dementia, disabilities and other chronic health problems are particularly at risk of abuse due to increased dependence on caregivers [10-12]. Caregivers' psychiatric disorders, previous history of victimization, poor social support, substance use, high levels of hostility and their dependence on the victim for accommodation and finance also appear to be associated with elder mistreatment [11,13-15]. Others reported shared living arrangement, social isolation, loneliness and caregiver strain as risk factors [13,16].

The 'mapping' of elder mistreatment occurrences and understanding of its risk factors and health consequences across cultures have been significantly limited by the narrow geographical base of current research, with most being conducted in economically developed countries. This distinct gap in the existing literature is reflected by the paucity of robust studies on elder mistreatment in low and middle-income developing nations. The 'identified' risk factors may be less pertinent or not fully applicable to the more conservative Asian cultures, considering the deeply ingrained concepts of family ties and filial piety. Wu and colleagues (2014) found that many Chinese viewed elder mistreatment as non-existent in their community owing to the traditional values and cultural norms which emphasize respect of, and provision of care for parents by adult children. On the contrary, their study findings showed that at least one-third of the interviewed older adults reported experiencing some forms of abuse, suggesting the pervasiveness and lack of awareness on elder mistreatment in the community [17]. One of the earliest attempt to quantify the elder mistreatment issue among the Asian older populations were conducted by Dong and colleagues who performed a cross sectional survey among Chinese older adults in a medical center in Nanjing, China. They found about 35% of elderly screened positive for elder mistreatment with neglect found to be most common form of abuse, followed by

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financial exploitation, psychological abuse [18]. Epidemiological evidence on elder mistreatment in this region remains apathy. Further research to determine the extent of elder mistreatment and the universality of its risk factors across different populations is necessary. Empirical data is essential to identify older adults at risk and facilitate the development of community-specific and evidence-based preventive measures.

Malaysia is a multiethnic and multicultural country with a population estimate of 29 million in 2014. According to the World Bank classification, Malaysia is an upper-middle income and developing economy situated in the East Asia and Pacific region [19]. Its population consists of mainly ethnic Malays (47%), followed by Chinese (25%), Indians (7%), and indigenous tribal groups (11%). Population projections predict that the number of people aged 60 years and above will form nearly 11 % of the national population by 2020, and this figure will double by 2040 [20]. This substantial increase in older populace, along with rapid urbanization and changing family structures will bring about greater challenges to the provision of care for the older person. Like many Asian countries, most older Malaysians rely heavily on their children for care and financial support. This is especially customary among those living in rural areas where there is inadequate pension and social support system and limited access to medical care, as compared to that enjoyed by their more affluent urban counterparts. The rural-urban migration of youths in search of better job opportunities has also greatly weakened the family's perceived obligation of caring for their elder members. The lack of social safety net coupled with heavy reliance on their children expose the rural older population to a greater likelihood of abuse and exploitation.

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A number of countries have enacted statutes for reporting elder mistreatment and protection of the elderly. There is no specific legislation to address elder mistreatment in Malaysia to date. The provision of the Domestic Violence Act 1994 is relatively non-specific; it covers all family members including older adults within a household [21,22]. Official or authenticated data on elder mistreatment is also unavailable to gauge the true extent of the problem. While the Malaysian government has demonstrated commitment to protect the rights and welfare of the elderly through a number of initiatives, there remains little information from well-designed community based research into the multiple dimensions of elder mistreatment. To address this need, the MAlaysian Elder miSTreatment pROject (MAESTRO) study was designed to estimate the prevalence and incidence of elder mistreatment, describe the characteristics of perpetrators, identify individual, familial, community and social determinants of elder mistreatment and assess its health consequences among a representative sample of Malaysian older adults.

Objective of the study and conceptual framework

The overarching aims of the study are to estimate the prevalence and incidence of elder mistreatment, its subtypes and multiple types of abuse; to identify the extent to which elder mistreatment is predicted by individual, familial, community and social determinants, and; to determine the consequences of elder mistreatment in relation to injuries, physical health and function, mental health, health utilization and mortality.

This project employed a conceptual framework adapted and modified from the World Health Organization. Applying the ecological approach, the framework guided the development of the

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study design and selection of the range of potential determinants and outcomes of elder mistreatment. The central thesis of this framework is the emphasis on the interaction and dynamics of multiple determinants at various ecological levels in which victims and perpetrators are embedded; individual, relationship, community and sociocultural. In this study, we examined both the risk factors for, and protective factors against elder mistreatment, along with its outcomes. Figure 1 illustrated the conceptual framework of this study.

[insert Figure 1]

METHODS AND ANALYSIS

Study design

This is a 5-year prospective longitudinal cohort study among community dwelling older adults aged 60 years and older and their caregivers, residing in the district of Kuala Pilah in the state of Negeri Sembilan, Malaysia. It commenced in November 2013 and is currently ongoing. The study will be executed in two phases. Phase I comprises a cross-sectional study (baseline) and phase II is a cohort follow-up study across a 5-year period. Participants will be followed up at 3rd, and 5th year.

Sample selection and Study participants

A two-stage cluster sampling was employed to select study subjects. In the first stage, one representative district, Kuala Pilah was randomly selected from seven districts available in the state of Negeri Sembilan. Negeri Sembilan lies in the central of Peninsular Malaysia, about 100

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kilometres away from the capital city, Kuala Lumpur. Its population stands at 1.02 million according to the national census. Compared to other districts, Kuala Pilah has the biggest population of older adults in the state. In the second stage, the Malaysian Department of Statistics (DoS) provided a comprehensive sampling frame based on the most recent national census conducted in 2010. Out of 254 enumeration blocks (EBs) within Kuala Pilah, 156 EBs were randomly chosen. Each EB contained a minimum of 15% of older individuals. A computer-generated list of households was then provided, from which 16-20 households were randomly selected from every EB. Maps of the local terrain provided by the DoS were used to locate selected households. The Malaysian Department of Statistics performs the national census every ten years and retains the most comprehensive and up-to-date information on the population demographics [20]. This method of complex sampling design ensured adequate coverage of older adults in all parts of the district, yielding a heterogeneous representative sample from the target population.

Respondents were interviewed at home by trained personnel, using a structured questionnaire. An older person and a caregiver limited per household were interviewed. For elder abuse screening questions, participants were interviewed in private without the presence of any family members, while their caregivers were interviewed separately.

Table 1 presents the eligibility criteria for subject selection in this study. Information gathered from respondents and caregivers included socio-demographic, physical health, medical history, nutrition, psychological status, daily activities, health utilization, and social support and network.

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Table 1 Eligibility criteria for the MAESTRO cohort study

Inclusion criteria	Exclusion criteria
• Older persons aged 60 years or more • Community dwelling elders living at home alone or with family or relatives in the past 12 months • Malaysian nationals • Elders who can communicate with the interviewers	• Elderly residing in long term care institutions • Elders who are unable to communicate with the interviewers, eg. post-stroke, mentally disabled, severe cognitive impairment. • non-resident in the area in the previous 12 months or foreign nationals

Recruitment and follow-up interviews Follow-up interviews will be performed on the 3rd and 5th year. Participants will be tracked for at least 5 years, or until death. To reduce losses to follow-up, a brief telephone interview will be conducted a year after the follow-up interview to detect any change of residence and health status in the past year. To gain rapport and ensure high response rate from selected subjects, the research team engaged actively with the local community via the Village Safety and Development Committee (VSDC). The VSDC acted as a mediator, assisting researchers in identifying selected house addresses and informing local residents about the possible visit by the research team.

Sample size calculation

Sample size calculation was estimated using the OpenEpi programme for cohort study. The minimum detectable risk ratio for primary outcome, mortality, among those exposed to abuse and non-abused was estimated to be around 2.28 [23]. The proportion of abuse is estimated to be an

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average of 15% based on a previous study and systematic review conducted [5,24]. Power and a 2-sided alpha were set a priori at 80% and 0.05. Design effect due to complex sampling was estimated to be 2.0. To account for loss to follow-up, the sample size was inflated by 30%. The calculated sample size required was 2418.

Assessment and operational definitions

Elder mistreatment

The primary outcome of interest is elder mistreatment. Older persons refer to those aged 60 and more, in line with the definition established by the United Nations World Assembly on Ageing, Vienna, 1982 and adopted by Malaysia. The definition of elder mistreatment was based on the WHO framework on violence: any abuse and neglect of persons age 60 and older by a caregiver or another person in a relationship involving an expectation of trust. Five types of abuse were measured including physical, sexual, financial, psychological, and neglect. In this study, we identified perpetrators as caregivers or person(s) whom the older adults know, or with whom they have a relationship.

An extensive review of literature was conducted [5], and we adapted and revised a comprehensive questionnaire developed by Naughton and colleagues [25]. Permission was sought from the national Irish prevalence study research team to use the instrument. This instrument was originally adapted from the revised Conflict Tactic Scale which was widely used [5]. In our study however, some items in the questionnaire were modified in order to contextualize elder mistreatment within our cultural setting. These items were behavior-specific, referring to the types of incidents that respondents may perceive as abusive. Behaviour-specific questions help

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cue respondents to think of relevant incidents and respond accordingly, thereby increasing the reliability and consistency of the reported incidents. The elderly were asked if they have ever experienced at least one incident of abuse, i) since turning 60 years old; or ii) in the past 12 months, by a caregiver or somebody with whom they have a relationship of trust. To further ensure cultural appropriateness, applicability and usefulness of the adapted abuse measures to the targeted population, the research instrument was pretested and reviewed by a panel of experts and face-to-face interviews with elderly. The measures was first translated from English to Malay language using the forward-backward translation technique, a standard procedure for questionnaire translation [26]. The instrument underwent a review by a group of local experts in public health, social work and services, physicians and geriatricians. Feedback were also sought from in-depth interviews with elderly on item content, readability, clarity, item interpretation and acceptability of survey procedures. There was general consensus that the proposed abuse questions measured the concepts being assessed. Additional items such as lack of access to food, clean clothing, medication or treatment, and shelter which was considered basic necessity for an older adult were included in the final instrument. The instrument was subsequently pretested with 350 elder respondents living in government subsidised residential area. The results of the reliability analysis suggest all abuse measures show fair to good internal consistency. The overall Cronbach's α for financial abuse, psychological abuse, physical abuse, sexual abuse and neglect were 0.728, 0.730, 0.685, 0.642 and 0.709 respectively. All abuse domains were significantly correlated with coefficients reported ranging from 0.10 to 0.86.

The list of acts is presented in Table 2. Physical, sexual and financial abuse are operationalized as any episode of elder mistreatment reported by older individuals during the reference period

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and perpetrated by a caregiver or a person in a position of trust. Subsequent questions gathered additional information on the frequency of events, perpetrators' characteristics, perceived seriousness, injuries sustained, respondents' disclosure (or lack of), the person to whom disclosure was made, and ensuing action following disclosure.

Similar to Naughton and colleagues' work and supported by literature elsewhere [7], psychological abuse is defined as 10 or more incidents of abuse. When the frequency is less than 10 it is considered to have happened if the episode(s) is perceived by the respondent as having a serious impact. There is no universal or standard definition of neglect. It varies considerably across countries and cultures. When adopting the definition of neglect, we took into consideration the Malaysian context and cultural ethos, in line with the National Policy on Elderly which emphasize older adults' rights to protection, welfare and dignity. In this study, neglect is defined as a caregiver's failure to meet the elder's basic needs such as access to medical treatment, adequate nutritional food, clean clothing, proper shelter, and clean and safe living conditions, or the failure of caregiver to provide assistance to the elderly for basic and instrumental activities of daily living. These include feeding, walking, using the toilet, dressing and bathing, preparing food, taking medication and so on.

Table 2: Operational definitions for elder mistreatment

Type of mistreatment	Definition
Physical	▪ Slapped, pushed, grabbed, or shoved ▪ Kicked, bite or hit with a fist or object ▪ Inappropriately restrained in any way, e.g. locked in room/house, tied in a chair, tied on bed, chained elderly ▪ Fed too much medicine or drugs to control ▪ Burned or scalded

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	▪ Threatened or assaulted with a knife, gun or other weapon
Financial	▪ Stole elderly's money, things, property or documents ▪ Purposely prevented elderly from accessing their money, possessions, property, land or important documents ▪ Manipulated or forced elderly into giving money or hand over property, land, possessions or other important documents ▪ Forced or manipulated elderly into altering their will or any other financial document ▪ Deliberately forge or signed cheques or other financial documents without elderly's permission ▪ Misused the power of attorney given by elderly or forcing or manipulating elderly into giving him/her power of attorney
Sexual	▪ Sexually harassed or talked in a way that made the elderly uncomfortable ▪ Touched or tried to touch in a sexual way against the elderly's will ▪ Forced or attempted to force to have sexual intercourse against the elderly's will
Psychological	▪ Cursed, shouted or insulted ▪ Humiliated, belittled or embarrassed ▪ Repeatedly ignored ▪ Threatened verbally ▪ Prohibited family members, friends or doctor/nurse from visiting or vice versa
Neglect	▪ Access to medical treatment ▪ Enough nutritional food ▪ Clean clothing, ▪ Adequate shelter, clean and safe living conditions ▪ Failure to provide elderly's need for support for basic activities of daily living when required such as feeding, walking, climbing stairs, going to the toilet, dressing and bathing.

Risk and protective determinants of elder mistreatment

Data will be collected from various sources including self-reports by respondents and their caregivers, and physical and clinical assessment. Table 3 shows the risk and protective determinants of elder mistreatment measured at different levels of the framework.

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Table 3. Matrix of determinants and its measurement

DETERMINANTS	MEASUREMENT
INDIVIDUAL (ELDERLY)	
Age	The age will be estimated based on the date of birth as recorded in the Malaysian National Registration Identification Card (NRIC). Where necessary, verification with other documents such as driving license, pension book or other government documents are performed.
Sex	Male or female as recorded in the NRIC.
Ethnicity	Ethnic status will be collected as recorded in the NRIC, mainly classified as Bumiputra Malay, Bumiputra non-Malay, Chinese, Indian or others.
Marital status	Based on current marital status as reported by the elderly, which will be categorized into married, single, divorced or widowed
Living arrangement	Living arrangement to be classified as own home, or others which includes children's home or relatives' home or other persons
Education	Elderly's level of formal schooling; categorized as none, primary, secondary or higher
Income	Elderly financial status will be measured by asking the amount of funding received every month in Ringgit Malaysia (RM). Various sources of support are recorded either current monthly income if working, monthly pension if pensionable, financial aid received through government, NGOs or official sources or estimated amount received from family members if any.
Current employment status	Elderly will be asked if they are currently employed in any capacity.
Co-morbidities (chronic diseases	Elderly will be asked if they had being diagnosed by physician for any chronic illness, which include high blood pressure, heart problems or blood circulation problems, stroke, joint pains or arthritis, Parkinson's disease, diabetes, breathing problems (asthma, lung infections) and cancer.
Physical disability	The Katz Index of Independence in Activities of Daily Living (Katz ADL), and Lawton Instrumental Activities of Daily Living Scale (Lawton IADL), are used to assess an older adult's ability to

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	independently perform self-care and maintenance. Katz activity of daily living has 6 items scored on a 3-point response scale (independent, some assistance, or dependent). Higher score indicates elderly's independence [27]. Lawton IADL has 8 items that assess independent living skills that are considered more complex than basic ADL A summary score ranges from 0 (dependent) to 8 (independent) [28].
Physical function	Two aspects of physical function of the elderly will be measured. i. Walking speed– average of two readings for 2.4m walking test in seconds ii. Muscle strength – average of two readings per hand for grip strength measured by dynamometer in kPa.
Cognitive impairment	The Elderly Cognitive Assessment Questionnaire (ECAQ) is a quantitative assessment of cognitive impairment among elderly people. A score lower than 6 are categorized as being cognitively impaired [29].
INDIVIDUAL (CAREGIVER)	
Caregiver demographic	Caregiver's age, sex, education, employment and household income level will be collected. Education, employment and income will be used as indicators to determine the socio-economic status of the caregiver.
Caregiver's substance abuse	Two items to measure caregivers' substance use including alcohol and drug problem.
Caregiver's mental illness or aggressive behavior	Elderly will be asked if their caregiver has any form of mental illness or aggressive behavior.
Caregiver caregiving and coping skills	Caregiver reactive assessment (CRA) with 24 items designed to assess specific aspects of the caregiving situation, including both negative and positive dimensions of caregiving reactions [30]
Caregiver's prior history of abuse	Caregiver will be asked if they have experience any form of child abuse or domestic violence in the past.
RELATIONSHIP	
Caregiver-elderly	Quality of the caregiver-care recipient relationship measures the

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relationship	quality of the current relationship in relation to general closeness, communication, similarity of views about life, and degree of getting along. It has four items on a 4-point Likert scale response [31].
Living arrangement	Current living arrangement will be categorized as own home, or others which includes children's home, relative's home or other persons
Caregiver depression	Depression Anxiety Stress scale (DASS) is 21 items self-report scale designed to measure the negative emotional states of depression, anxiety and stress experienced by the caregiver [32]
Caregiver burden	Brief COPE is a brief measure with 28 items assessing caregiver's burden and coping mechanism. Higher scores indicate ineffective coping mechanism [33].
Dependency of elderly or caregiver	Two items that measure elderly's fear of abandonment, loneliness and tolerant towards aggressive behavior.
Religious commitment	Salience in religious commitment scale is used to measure the extent to which elderly and their caregiver consider their religious beliefs to be important both in general and decision making. The scale has only three items on a 4-point Likert-type scale. Total scores range from 3 to 11 [34].
COMMUNITY AND SOCIETAL	
Social support	The Duke Social Support Index (DSSI) has 11 item that measure social support received by the elderly. The higher the score, the greater support perceived by elderly [35]
Social isolation	The Lubben Social Network Scale (LSNS-6) is used to screen for social isolation among community-dwelling older. A score of 11 or less on the LSNS-6 indicate social isolation [36].
Social cohesion	The social cohesion and trust domain from the Collective Efficacy Scale (CES) is utilized. It was a 5-item Likert-type scale asking how strongly they agreed to the statements regarding people around their neighbourhood [37].

Health consequences of elder abuse and neglect

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As delineated by our conceptual framework, consequences of elder mistreatment are categorized into quality of life, mental health, physical health/ function and mortality. This study will therefore explore four scopes of outcomes: quality of life (QoL), mortality, morbidity and health utilization. For morbidity, physical function (gait speed) and mental health (depression and sleep disturbance) will be measured, whereas health utilization is represented by hospitalization rate and frequency of health visits.

Quality of Life

The Short Form Health Survey SF-12 is utilized to measure health-related quality of life in this study. The SF-12 has both physical (PCS) and mental component (MCS) summary scales which comprise eight concepts: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality (energy/fatigue), social functioning, role limitations due to emotional problems and mental health. Each item has a rating scale of 0 to 4.The Malay version of Short Form Health Survey (SF-12) has been validated [38] and will be used in this study.

Mental Health

Two variables will be measured in this sphere: depression and sleep disturbance. Depression will be assessed using the fifteen-item Geriatric Depression Scale (GDS-15). Respondents will be asked whether they have experienced the symptoms described during the past week using the yes/no format. A score of greater than 6 suggests symptoms of depression. The GDS-15 has been validated among the Malay elderly population and found to be reliable, with Cronbach's alpha = 0.84, test-retest reliability= 0.84 and concurrent validity with the Montgomery–Asberg Depression Rating Scale (Spearman's rho 0.68) [39].

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Sleep disturbance is measured by the Pittsburgh Sleep Quality Index (PSQI), a validated nineteen-item questionnaire which is used to study the quality and pattern of sleep among older adults. Seven domains of sleep are captured by this instrument: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications, and daytime dysfunction over the last month. Respondents are asked to rate each of these seven component on a scale of 0 to 3, with 3 reflecting the negative extreme on the Likert Scale. A score of 5 or more indicates 'poor sleep' or sleep disturbance. The PSQI has a Cronbach's alpha of 0.83 for all its seven components, and has been said to show high validity and reliability when used among older adult populations across countries [40].

Mortality

Data on mortality is obtained by regular contact with respondents' family members and caregivers. Reported deaths will be crosschecked with the National Registration Department database, which provides additional information such as the date and cause of death.

Physical health/ function

Gait speed will be quantified as an indicator of physical function. In gait speed assessment, respondents are asked to walk for 4 meters with or without walking aids, and the time taken is recorded. Each participant undergoes the walking test two times, and the best score (time) is taken. Walking speed has been reported to be a good predictor of adverse outcomes in community-dwelling older people [41] and was associated with survival of older individuals [42].

Hospitalization and health visit

Hospitalization is defined as being admitted at any hospital (public or private) for at least 24 hours in the last 12 months.

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Hospitalization and frequency of health visits are determined by two questions:

1) 'In the last 12 months, did you ever visit any of the following health facilities?'

2) 'How many times did you visit?'

The answer options include 'private clinic,' 'government clinic,' 'social service officer', 'outpatient department at a hospital,' 'emergency department,' and 'admitted for at least 24 hours.' Frequency options are given as 'never', 'once', '2-3 times', '4 times or more', '1-2 times/week' and 'everyday'.

Statistical analysis plan

Data entry and management will be conducted using the SPSS Version 21.0 software program. Double entry method will be performed using standardized coding and labeling approach. All questionnaires will be checked after the fieldwork by a second person to minimize missing data. Any missing data will be investigated and where possible, the respondent will be contacted via telephone. Information collected will be kept in a locked space to which only designated personnel have access. Secondary data (mortality) will be collected from the national registry.

Data will be presented as mean ± standard deviations, percentages, odds ratios (for cross-sectional analysis) or relative risks (for longitudinal analysis). The prevalence (or incidence) of elder abuse, its subtypes and related factors will be estimated according to age and gender. Outcomes will include mortality, quality of life, mortality, physical function (walking speed), mental health (depression and sleep disturbance), and health utilization (hospitalization rate and frequency of health visit). Normality of the data sets will be tested for parametric tests. Student t-

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test or analysis of variance will be used to compare variables among the different groups for continuous data. For comparison of proportions, chi-square analysis will be performed. To investigate the associations between outcomes and studied parameters, multivariate analysis will be employed. Possible confounding factors found in univariate analysis will be adjusted in multivariate analysis. The relationship between various risk factors and abuse estimates are subjected to logistic regression models. Cox proportional hazard regression models will be performed to predict the effect of abuse on time to each outcome, e.g. risk of mortality. A survival curve will be constructed to enable 'time-to-event' analysis and comparison between those abused and not abused. The relationship between elder abuse and annual rate of hospitalization and health visit frequency will be calculated using Poisson regression models. Complex sampling regression analysis will be performed, taking the sample design into account. This procedure will estimate variances by taking into account the design used to select the sample, which is probability disproportional sample without replacement in this case. P value of less than 0.05 will be considered statistically significant and 95% confidence interval will be reported where appropriate.

At subsequent follow-ups, respondents will be compared to non-respondents with respect to characteristics such as sex, age, educational level and health status to detect any systematic differences between these two groups.

ETHICAL ASPECTS

The study protocol was submitted to and approved by the Medical Ethics Committee of the University of Malaya Medical Center (MEC Ref 902.2) and Malaysian National Medical Research Register (NMRR-12-1444-11726). Written permission from the relevant authorities at

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the community level was also obtained. Respondents' written, informed consent was undertaken prior to the baseline interview. The participation of both older adults and their caregivers was voluntary. Any information provided by the respondents to the interviewers remain confidential and anonymous. The purpose, risk and benefits, were explained making clear to the respondents that they can opt out or withdraw at any time without affecting their rights to access to medical care or social welfare services provided in the public facilities.

Safety protocol

Participating in research involving sensitive topic may have an impact on the older adults' and the interviewers' safety and wellbeing. Disclosure of abuse or identification of abuse victims may worsen the existing problem through either retaliation by the perpetrator or further isolation of the victims. Other ethical dilemmas include the obligation on the researcher to take the right action upon identifying abuse victims, and the manner in which questions on abuse are being asked due to the sensitive nature of this subject. To minimize possible threats and risks, one older person and one caregiver per household was interviewed and they are interviewed in separate occasions. Interviews were held in private and without the presence of family members, caregivers or a third person. Appointments were made with selected respondents via telephone prior to the interviews to ensure privacy and prevent imposter interviewers from gaining access to older person's residence. The interviewers were assigned in pairs to visit each selected household, a strategy undertaken to ensure the safety of team members. The research team informed the local police stations and local residential committees about the data collection. The potential respondents were able to verify the authenticity of the survey with the police, residential committees or health district office.

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All respondents were provided with various hotline numbers to report abuse including hotlines dedicated for domestic violence and child abuse such as Talian Nur 15999, Teledera toll-free hotline 1-800-88-3040, and the contact numbers of social workers and counselors available in the district. In the event of disclosure of abuse during the interview, respondents would be advised to discuss strategies to deal with this problem with family members or a trusted person. They would also be referred to the social worker or health officer of the district if circumstances were judged to be life-threatening, or if direct requests were made. Respondents' rights and autonomy were observed during the entire research process.

Prior to the conduct of the study, a two day training session were held for all interviewers to familiarize with the study objectives, methodology and research safety protocol. The topics covered include general topics on elderly and aging process, types of abuse and neglect, interviewing techniques, ethics of conducting sensitive topics, communication skills, and stress management. The session also included role play, mock interviews, group discussions and appropriate responses when handling difficult situations such as an elder respondent who could be hostile, got upset or cried during the interview. A medical doctor and two counsellors who were part of the research team provided emotional support when necessary.

For interviewers, it is important to be able to talk with other team members about the feeling evoked from the interview process. The process can be emotionally demanding. At the end of each surveyed day, regular meetings were held between the interviewers and researcher to check for questionnaires completeness, discussed any difficulties faced during fieldwork, and identified cases required referrals to the district health or social welfare offices. During the data collection

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period, debriefing sessions allowing peer sharing and exchanging experiences were conducted for the interviewers every week by two counsellors in the research team.

DISCUSSION

The MAESTRO cohort study aims at estimating the prevalence and incidence of elder mistreatment, identifying its risk factors and characteristics of perpetrators, and assessing mortality and its health consequences among community-dwelling older Malaysians. This study is one of the pioneering prospective cohort studies that explore the issue of elder mistreatment in this region, particularly among South East Asian countries.

There are several strengths of this study. First, the prospective study design with a long follow-up period is appropriate to determine causality between predicted outcomes and exposure (abuse and neglect). We focus not only on epidemiological characteristics of elder mistreatment, but also the relationship between determinants at different levels and elder mistreatment. This study thus is able to evaluate the impact of social environment and elucidate other risk factors of abuse. Second, we are able to follow-up a group of respondents who report having experienced abuse, and assess a range of outcomes including mortality, morbidity and health utilization. Active recruitment and face-to-face interview ensured a highly personalized contact with respondents to increase the response rate. Of the total 2,496 elderly respondents listed in the sampling frame used for the survey, our preliminary analysis estimated 2,118 older adults participated and interviewed for the baseline study, giving a high response rate of 84.9%. Approximately 378 older adults did not participate in the study. Reasons for non-participation were: refusal (33%), living elsewhere/not at home at the time of study (31%), ineligible (11%), death (9%) and others

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(16%). Face-to face interviews were useful to obtain more accurate information as older respondents who have difficulty understanding can directly ask the interviewers for explanation. This is a practical approach particularly in settings where a large proportion of the older populations are still illiterate or with minimal education. Using the census provided by the national Department of Statistics as our sampling frame, the MAESTRO study subjects can be considered representative of the Malaysian rural older population.

One major limitation of this study is the locality in which data was collected. As the focus in on rural community dwelling older adults in the district of Kuala Pilah, generalizability of our study findings to the urban elderly populace could be an issue. Results from this study however will provide robust evidence and re-inforce the need for programmes to raise awareness, and interventions at the appropriate level to address elder abuse and neglect in Malaysia. Another limitation in our study is the absence of measurement for dementia status as a risk factor or covariate. Also, older adults living in care homes, post stroke or with severe cognitive impairment who are most at risk of elder mistreatment were excluded in this study, likely to underestimate the magnitude of elder mistreatment. This is a double-edged sword situation, balancing between the need for respondents to fully understand and respond to questions accurately, or exclusion of high risk groups that might add to underestimation of the elder mistreatment problem. We included measures of cognitive functioning such as ECAQ to gauge the respondents' cognitive capacity to consent to participation and ability to provide information as accurate as possible.

Upon completing the baseline assessment, we gathered a number of lessons which would be useful for other researchers when conducting a similar study. Active engagement of the local community is extremely important. In rural areas where the social fabric is largely intact and

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dynamics of social structure is different from that of the urban community, getting the local leaders or influential figures of the locality into the picture will facilitate rapport building with residents and smoother data collection. It is crucial that the research team listens to the local people's needs and suggestions, understands their cultural norms and expectations, and always attempts to create a win-win situation throughout the research processes. Employing local people as part of the research team can be an effective strategy to win the trust of the local community, as the presence of familiar faces will make the elderly feel 'at home' rather than viewing the researchers as outsiders who should be treated with suspicion. In our case, we got several authoritative bodies involved; the local leaders, local police force, local health workers, district office, Ministry of Health, and Ministry of Rural and Regional Development. Engagement of multiple and cross-sectoral partners not only ensures researchers' safety but increases accountability and transparency of the research process.

With regards to a sensitive subject like abuse and neglect, an ethical dilemma might arise as to what is the subsequent action by the interviewer upon identifying abuse victims. Indifference or lack of response by the researcher may create misunderstanding among the local elderly, apart from going against the principles of ethics in research. Researchers and interviewers involved in the researching sensitive topics should be aware of their own behaviour and the effects of the study on the participants. The research process itself might affect the researchers' values, emotions and standpoints. Researchers may need support or supervision for themselves while listening to heart wrenching experiences of older adults or dealing with sensitive issues concerning family life. The interviewers shared their thoughts and feelings on the project, inner personal reflections of their behaviours and attitudes and role playing various real-life scenarios

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encountered during the fieldwork. The counsellors discussed the groups' collective experiences for everyone's benefit, drawing upon constructivist debriefing methods used in counselling [43]. These sessions were helpful to reduce burden, stress and anxiety accumulated during the interview process and also improved team dynamics and productivity in our study.

To increase respondents' privacy and protection, we asked respondents whether they were in a place where they could talk alone or in private. It was important to conduct the interviews in a safe and comfortable environment or when the respondents were ready to be interviewed. The strategy to assign two interviewers per household was effective, with one person interviewing the elder, while the other could engage with family members if present, so as to allow better privacy between the interviewer and the elderly respondent. While asking questions on abuse/ neglect, the respondent is interviewed alone without the presence of any family members or caregivers. There were no adverse events or complaints reported during the conduct of the baseline assessment study, hence the concern that the victims potentially at risk of subsequent abuse due to their participation were minimal. Although the interviews itself might add temporary suffering to the respondents while recounting their experiences, it was also an opportunity for them to deal with their painful experience and facilitate the healing and recovery process.

Adequate information on the local resources, healthcare and social support system is crucial to identify the channels through which abuse victims can receive help. We collaborated with the local health district office and engaged local health personnel and social workers, in order to facilitate referral of abuse victims for further assessment and assistance. The research team referred 28 cases to the State Department of Social Welfare or Department of Health for further assessment and follow-up upon interviewee's consent. However, being a relatively new issue in the healthcare system, limitations were inevitable: we were uncertain of how fast the referral

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process worked, and whether follow-up was done accordingly. Lack of expertise was another overwhelming issue. Health workers comprised mainly medical officers with no official training in geriatrics or gerontology. Consequently, the research team in collaboration with the Health State Department provided a series of training on detection and management of elder mistreatment for all the district medical officers and nurses working in public health facilities.

Incentives are without doubt an effective strategy to encourage participation in a cohort study. We provided both pecuniary and non-pecuniary inducements at different phases of baseline assessment. Our observation was that, despite pecuniary incentive being more attractive, it has a number of drawbacks. Collecting data in a rural setting forced our team members to carry huge amount of cash from one place to another, which was highly risky and unfeasible. There were attempts by some respondents to profit from what was offered, thereby creating ill feelings and resentment. Non-monetary incentives in the form of small gifts and souvenirs were found to be more reasonable and practical.

Logistics plays a huge role in determining the flow and success of research processes, mainly data collection. When conducting studies in rural areas of developing countries where the local topography has not been properly mapped out, researchers need to anticipate few issues: the available map may outdated as the last national census was conducted in 2010, so locating addresses can be a challenging task. Some areas can be difficult to reach via ordinary transportation, and previous physical construction or infrastructure might have undergone transformation at a speed faster then what those in charge of survey and mapping are able to track. While locating the addresses of study subjects, we encountered difficulties as mentioned above, despite being provided with maps of the neighborhood.

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In conclusion, the MAESTRO study is one of the first few cohort studies exploring the issue of elder mistreatment in the South East Asian region. It will greatly contribute to a better understanding of the subject of elder mistreatment among older adults in a middle income and developing country. The lessons we learnt in the initial phase of the study are valuable, and will act as a guide during the next phase.

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COMPETING INTERESTS

No conflict of interest has been declared by the author(s).

AUTHORS' CONTRIBUTION

CWY, NNH, RS, RY, FH, NI, and SK conceived the study design. CWY, NNH, RS and RY prepared and drafted the manuscript. SNA, IAR, ZMA, SO, FHM, TMP, PB and AB contributed to the study protocol in their areas of expertise. RS, SK, NI, RY, DP, SNA and IAR were involved in acquisition of data. CWY and NNH were the principal investigators and led the grant application. All authors approved the final manuscript.

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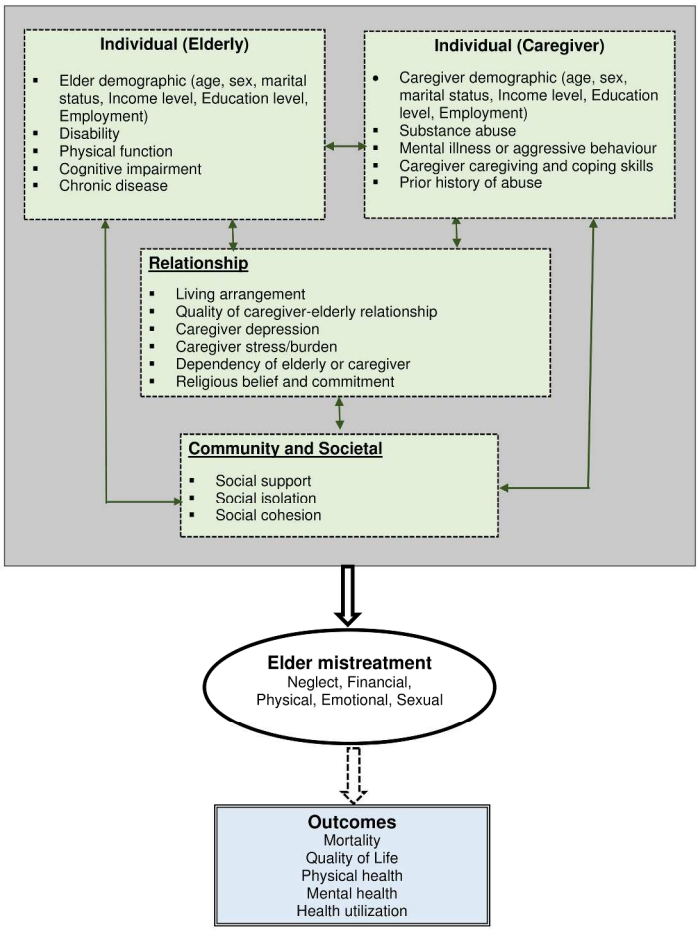
Figure 1 Conceptual framework of this study



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