



EAPU Reference Group Research Subgroup – Final Summary

A 'wishlist' for a prevalence study

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Published 3 February 2015

Preface

The formation of the Elder Abuse Prevention Unit (EAPU), Reference Group Research Subgroup was an EAPU initiative to canvass the priorities of services in the elder abuse sector in relation to a prevalence study of elder abuse in Queensland. Most members of the EAPU subgroup were not professional researchers; the meetings and this document are intended to represent a preliminary scoping exercise rather than a research proposal or literature review. The aim of the report is to document the interests of service level stakeholders with regard to an elder abuse prevalence study. It is the hope of the EAPU that the positions presented in this document will be considered by any research team undertaking an elder abuse prevalence study in Queensland.

Members of the EAPU reference group formed the subgroup and included representatives from the Public Advocate, Brisbane Seniors Legal and Support Service, Queensland Department of Communities, University of Queensland and UnitingCare Community. The group also sought input from UnitingCare Community's, Older Persons' Programs' Indigenous worker. The group met three times, initially to discuss the issue of defining elder abuse and the implications for study parameters, then to discuss international examples of elder abuse prevalence studies.

This report is a product of the ideas and discussion arising from these meetings but does go beyond the subgroup discussions. The EAPU gratefully acknowledges the contributions of the members and endeavours to be clear in its attributions. The EAPU believes that this report accurately reflects the discussions of the group and takes responsibility for any omissions or errors that it contains.

The UnitingCare Community Elder Abuse Prevention Unit (EAPU), is charged with contributing to the prevention of elder abuse in Queensland. The EAPU's foremost primary prevention activity is community education and awareness raising. An elder abuse prevalence study that is unique to Queensland would be beneficial to the EAPU in a number of ways. For the prevention aspect of the EAPU's work, a prevalence study would provide the EAPU the ability to strategically target and then monitor the impact of training and awareness initiatives. For the EAPU Helpline which provides information, support and relevant referral advice for people who are in an abuse situation, a prevalence study and the associated profile of victims would enable the EAPU to gauge whether those who are likely to experience abuse are aware of the service. More broadly, a prevalence study would also provide an academic baseline and support further research on elder abuse in Australia.

The EAPU has long advocated for the undertaking of a prevalence study into elder abuse. The increase in calls to the Helpline each financial year, and international media reports of an increase in the incidence of elder abuse (e.g. "Disturbing rise", (2013)) have prompted a renewed urgency for a quality prevalence study. At present we are unable to say that elder abuse is increasing, even though the experience of the Helpline workers is that there is a higher demand for services. It seems quite likely there will be an increase in the number of elder abuse cases, given the number of people moving into and staying in the 'elder' category as the baby-boomers age and longevity increases. However, there may be an increase in the proportion of older people experiencing abuse as well as the increase in the number of older people. The EAPU sees that there is a risk of an increase in the prevalence of elder abuse for a number of reasons including a policy shift to user-pays systems of aged care; Helpline narratives suggest that some older people may experience abuse as family members seek to retain assets rather than spend them on care. The EAPU sees that at this point an elder abuse prevalence study would greatly assist in understanding the growing problem of elder abuse in Queensland as well as targeting and measuring the effectiveness of interventions.

Defining elder abuse

Although there is *prima facie* consensus on the definition of elder abuse around the world, a unified operational definition has proven elusive. For EAPU, input onto the operational definition of elder abuse was the most important function of the subgroup. The subgroup provided clear direction on the relational element of the definition and as a result of further examination of the issue, the EAPU proposes additional criteria for abusive spousal relationships to be considered elder abuse rather than spousal abuse.

The definition used to guide the EAPU and many other services locally and internationally is the definition adopted by the World Health Organisation (2002):

"Elder Abuse is 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 older person"

That abuse must occur within a relationship of trust is a critical feature of elder abuse. However there is a great deal of variation in what is reported to constitute a relationship of trust. In a jurisdiction such as Queensland where legal interventions for elder abuse rely on a range of legislation such as the Domestic and Family Violence Protection Act, Guardianship and Administration Act, and the Criminal Code Act there is no legal definition to refer to and therefore the option is to consider definitions in the research literature and definitions used to guide services. It is important to acknowledge that definitions in use by researchers are not necessarily the most appropriate to guide service provision. Services that support older people may be better served taking a more holistic approach and using a more flexible definition that includes perpetrators outside the relationship of trust. However, for the purposes of a prevalence study the subgroup deemed that a research definition is required.

There was much discussion regarding the definition of the relationship of trust and the subgroup concurred that 'elder abuse' was confined to those in a social-role based relationship of trust. Further, that the roles that constituted a relationship where there was an expectation of trust were restricted to family, 'friends-as-family' and informal carers. Neighbours, scam-artists, and perpetrators of crimes such as theft or assault are not considered to be in a social-role based relationship of trust and would not be considered as perpetrators of elder abuse even though they may form a relationship with the intent to victimise the older person. The inclusion of friends-as-family is important and especially relevant for some members of our community, including older lesbian, gay, bisexual, trans/transgender and intersex LGBTI persons who, as a result of cultural attitudes may have little to no contact with biological family and have developed a close network of friends that take on the role of family.

Importantly, workers of all kinds: aged care, community care, and private care staff are excluded from the definition of elder abuse for which a prevalence statistic is considered desirable by the subgroup. This is divergent from much elder abuse literature; abuse by care staff is commonly included in elder abuse research in Australia and internationally. However, the subgroup saw that rather than expectations being derived from a social-role, in a worker-client relationship expectations are managed by some form of consumer contract – whether that be an explicit, individual contract or an implicit contract governed by local consumer law. Abuse by care staff was acknowledged as a serious problem but for the subgroup it was seen as a separate issue that was associated with worker misconduct, systemic issues within organisations, and individual perpetrator psychopathology or criminality.

The subgroup also considered that elder abuse is different to spousal abuse in older age. It finds untenable the premise that a victim who has been in a relationship of spousal abuse since age 20 suddenly becomes a victim of elder abuse when they have their 60th birthday. Spousal abuse is present within older age groups and it is the subgroup's view that a prevalence study must include some way to distinguish between aging relationships, or new relationships in older age, in which spousal abuse occurs; and between abuse that occurs within spouse/partner relationships because of, or triggered by an age related factor. The EAPU does hear of cases where it considers that elder abuse is occurring within a spousal relationship. Usually such cases involve the onset of age related functional or lifestyle changes for one partner but not the other and this can be due to an age gap, or simply differential aging. Although it is tempting to attribute this to carer stress model, a care burden on the perpetrator may not actually be present - other family or community and private care services may take on this role.

The EAPU has not found literature that discusses this idea of elder abuse requiring an age related trigger as well as an 'old' victim, but sees this an important discussion in the development of a model of elder abuse. Similarly, the EAPU has not found a prevalence study that distinguishes between spousal abuse and elder abuse. Existing studies limit themselves to measuring abuse tactics experienced by older people and the relationship to who perpetrated the abuse. As a result the outcome of some such studies is that spouse/partners are found to be the largest group of perpetrators of elder abuse. For the EAPU, being able to distinguish between the two categories – elder and spousal abuse – in a prevalence study is essential, though it recognises that this would be challenging given the lack of theoretical work on a model of elder abuse. The EAPU suggests that for a prevalence study spousal abuse could be distinguished from elder abuse through comparison of relationship duration and abuse duration e.g. abuse that has existed for the entire or substantial majority of the relationship could be categorised as spousal abuse.

Target Population

Gender

The subgroup recognises elder abuse as a form of family violence in which both women and men are victims. Although women are more likely to experience elder abuse than men, men consistently make up approximately 30% of victims disclosed to the EAPU Helpline. As such, the sample should include both females and males.

Age

The subgroup discussed the inadequacies of age-based criteria for 'elderly', noting that notions of what constitutes 'elderly' changes with cultural shifts and longevity increases. Similarly, it was acknowledged that there is substantial variance of the impact and onset of the age-related issues that are associated with defining the 'elderly' as a particularly vulnerable group. However, the subgroup concluded that criteria must be set, and that a prevalence study would be best served keeping in line with the benchmarks of previous international research as well as those used for eligibility for aged services such as Home and Community Care. The age criteria was recommended at 60 for both males and females.

Location

Gaining an accurate understanding of the geographic location of abuse emerged as a priority for a number of subgroup members. Although this entails significantly higher sampling costs in such a large state compared with cluster sampling methods, the benefits to services and agencies are substantial, in particular to inform allocation of support and intervention resources.

Residence

The subgroup discussed whether the target population should be all persons 60 years and over, or only those living in the community. Although prevalence for all persons over 60 years would be desirable it was noted by the member researchers that residential facilities present substantial challenges to the integrity of random sampling. This is largely due to the inability to include residents in most facilities in true random sampling methods. Although a prevalence study would ideally capture prevalence for all older Queenslanders, the subgroup strongly prioritises the fidelity of the prevalence rate and consequently prefers restricting the target population to community dwelling persons 60 years and over than reducing confidence through the inclusion of residential facilities. The EAPU also notes that the controlled environment of residential facilities and resulting ease of sample access has resulted in a greater number of studies utilising residential samples.

Decision making capacity

The question of whether the study should attempt to determine elder abuse of those with impaired capacity was discussed. The nature of severe capacity impairment means that it is not possible to obtain reliable reports of abuse from the victims themselves. As a result it is not possible to accurately determine a prevalence of elder abuse for older people with impaired capacity. The avenue available for investigating abuse requires surveying the older person's guardians, family or carers. There are numerous obstacles to obtaining reliable responses from such proxies: older people may have experienced abuse which their carers have no knowledge, or the carers may be perpetrators of abuse and therefore unlikely to disclose abuse to interviewers. Again, the subgroup prioritises fidelity of the prevalence statistic and recommends that the target population should be older adults without substantial decision-making impairment.

On the topic of screening for capacity, the subgroup was of the opinion that no formal screening should be undertaken. That all candidates who had the capacity to participate in the interview would be included: qualified and trained interviewers would make the determination on the basis of the respondent's demonstrated capacity to engage with the interviewer. As age-related deficits of memory and decision making capacity are considered to substantially increase an older person's vulnerability to abuse, the subgroup considered it important to strive for inclusivity, and that the older person should be supported by the interviewer to complete the survey even where some impairment is apparent.

Older Aboriginal and Torres Strait Islander persons

The subgroup discussed the question of determining the prevalence of abuse by family of Aboriginal and Torres Strait Islander older people. In particular the discussion focused on the significant cultural differences in defining family and the expectations held by family members. The need to take time to develop trusting relationships with Aboriginal and Torres Strait Islander communities to facilitate participation in research was also raised. The consensus of the subgroup was that the abuse of older Aboriginal and Torres Strait Islander persons require not only a separate and dedicated prevalence study, but also that further research would need to be undertaken to investigate and validate the concept and operational definitions of elder abuse for Aboriginal and Torres Strait Islander communities. With respect to Aboriginal and Torres Strait Islander respondents identified in the course of a general prevalence study method, the subgroup agreed that such respondents should not be excluded. The EAPU wishes to emphasise, however, that many aboriginal communities have identified that family violence is a growing concern and that the provision of services or other initiatives identified by individual communities, or the broader community, should not be delayed for want of a prevalence study.

Culturally and Linguistically Diverse (CALD) communities

The subgroup also discussed the question of whether specific efforts should be undertaken to ensure that CALD groups are represented in the sample. Issues were identified relating to the cultural variations in definitions of family as well as expectations of family. Further observation was made that the profile of CALD communities changes quickly with patterns of migration, limiting the predictive value of specific sampling of CALD communities. The subgroup concluded that prevalence rates within specific CALD communities should be obtained by separate dedicated studies in consultation with those communities. Again however, members agreed that CALD respondents identified by the sampling method should not be excluded.

Method

Prevalence Type

A life time prevalence – abuse since age 60 – as well as a 12 month prevalence was considered desirable.

Sample considerations

The consensus of the subgroup was that the target sample would need to be representative for both age and gender. EAPU considers that there should be a representative sample in 10 year age groups from 60 – 69, 70 – 79, and 80+.

Sample Method

The priority of the subgroup is to obtain a prevalence statistic, and therefore requires a random sampling method. Although cluster sample methods offer substantial cost efficiencies, it emerged that for some Queensland stakeholders there was a strong desire to have a geographic understanding of where abuse is occurring. As such the sample area would need to be state-wide. The practical implication of this identified by the member researchers was that is that the initial identification of participants would need to be via random-digit dialling. The integrity of random digit dialling was discussed given that households are moving away from land lines to mobile phones, but it was concluded that this is unlikely to be an issue with the current generations of older Queenslanders.

Survey Method

With regard to how to administer the survey instrument, the notion of paper surveys was immediately dismissed: paper surveys have generally poor response rates and this is likely to be exacerbated in a population where the incidence of visual, cognitive and fine motor impairments is high as a result of aged related decline. The notion of a call-centre style telephone survey had also come to be seen as inadequate through the discussion of capacity: the desire for inclusiveness results in a need for highly qualified interviewers in preferably face-to face interviews to ensure that older people with some capacity impairment are supported to participate. In addition the benefits to the participants of face-to-face interviews were raised. For example, the ability support the respondent through the disclosure of abuse, ensuring privacy during the interview, ability to use technological aides to allow participants to respond privately and non-verbally to sensitive questions such as relating to sexual abuse, as well as the ability to identify a need to provide the older person with referrals should the older person reveal an active abuse situation or become significantly distressed as a result of disclosure. Although face-to-face interviews were seen as the ideal, the realities of the Queensland geography were not dismissed. The subgroup thought that where face-to-face interviews were not possible, telephone interviews by the same interviewers would be acceptable.

International studies examined

A number of recent international prevalence studies were discussed with reference to their suitability as a model for a Queensland (or Australian) prevalence study. All the studies operationalised abuse by either adopting or modifying the Conflict Tactics Scale (CTS2) which is a tool for measuring interpersonal violence that is commonly used in studies on spousal violence. The scale covers psychological, physical and sexual abuse and, as noted by (Sooryanarayana, Choo, & Hairi, 2013) peer-reviewed studies using the CTS2 have good validity and reliability of results. Methods of assessing neglect and financial abuse varied across the studies. A matrix of the operational definitions can be found in Appendix A.

Abuse of Elderly in Europe (ABUEL)

The first study discussed was the ABUEL. The ABUEL was a multi-national survey administered in Germany, Greece, Italy, Lithuania, Portugal, Spain, and Sweden. The survey instrument itself was large and consisted of a number of measures including demographic information, lifestyle factors (smoking and alcohol), social support (using the MSPSS), utilisation of health and care service, diseases and medication, the Giesson Complaint Questionnaire, the WHO quality of life questionnaire, the Hospital Anxiety and Depression Scale, leisure activities, religion, stressful life events screen questionnaire, and the Post-traumatic Symptom Scale (PTSS-10), as well as abuse measures for psychological abuse, physical including sexual abuse, and financial abuse. These abuse measures were adapted from a UK study and the CTS2. On examination, the ABUEL has many more questions relating to psychological, physical and sexual abuse than the UK study it drew from. To the subgroup, the ABUEL appeared excessively long both overall and in its abuse questions. Examination of the instrument also raised concerns that the measure of financial abuse did not include situations where the perpetrator is failing to contribute to household expenses, and represents a significant drain on the victim's resources. However a positive was that the measure recorded some perpetrator characteristics and the inclusion of the WHO quality of life questionnaire was considered desirable.

Although the ABUEL has produced a report of the results, the data-set is conspicuously absent amongst peer-reviewed journals. The group also noted with some concern the very high rate of psychological abuse 19.4% compared with peer-review studies such as the Irish study where psychological abuse was 1.2%. Spouse/partners were the largest group of perpetrators for all abuse types measured except for financial abuse. Overall the ABUEL seems likely to have suffered from methodological problems resulting from different sample selection and survey methods employed in the member countries which can be exemplified in the response rates which varied from 18.9% in Germany, to 87.4% in Portugal (Lindert, 2012).

Study of Abuse and Neglect of Older People (the UK study)

The subgroup examined a group of three studies, one each from the UK, New York and Ireland. The UK study (O'Keeffe, 2007) was chronologically the first study and the operational definition and the instrument they developed has either been adopted by or adapted for a number of other studies (including the ABUEL). This is largely to do with the extensive work and consultation that was undertaken in its development. The development of the UK survey was guided by previous elder abuse research in the initial phase. The researchers then sought extensive feedback from older people, carers and protective service workers. The feedback was incorporated into the instrument, which was then tested and revised in a piloting phase (De Donder et al., 2011).

The subgroup considered the UK study's use of computer-assisted response as especially useful for confronting questions regarding sexual abuse. The UK study leveraged off government commissioned national health survey. The health survey participants were a nationally representative random probability sample and these participants were asked to participate in the elder abuse study. The survey instrument itself consisted of demographic and socio-economic questions, health and care requirements, mental health and wellbeing (CASP, CESD) as well as questions on the perception of mistreatment of others in a care home or hospital and attitudes towards growing older.

The abuse measures developed included 8 items for financial abuse, 6 for psychological, 11 for physical, 7 for sexual, and a measure of neglect (see appendix A). Of interest to the EAPU was an item that appeared in the survey instrument "Stopped contributing to household expenses such as rent or food where this had been previously agreed" but was not apparently included in the items that made up the operational definition of financial abuse. This item however, appears in the operational definition of abuse used in the Irish study.

The UK study resulted in a 2.6% prevalence of any type abuse in the past year which increased to 4% if neighbours and others were included. Overall, incidents of mistreatment involved 51% spouse/partners, 49% other family, 13% care workers, 5% close friends (multiple perpetrators types could be reported for each mistreatment) (O’Keeffe, 2007) .

Under the Radar: New York State Elder Abuse Prevalence Study (the New York study)

The New York study (Lifespan of Greater Rochester, Inc. & Weill Cornell Medical Center of Cornell University, 2011) drew on the UK study as well as a Canadian study in the development of their measures. The New York prevalence study was a telephone survey and used quite a small instrument. Non-abuse questions were limited to basic demographic and household information and the EAPU considers that an analogous instrument for Queensland would be insufficient. The New York study’s operational definitions of abuse contained many similarities to the UK and Irish definitions, but the EAPU considers some New York items indicative of a broader definition of elder abuse that included poor interpersonal relationships. For example, the items “Sulked or refused to talk about something” and “Done or said something to spite you?”. The New York study also raised concerns for the subgroup in its use of proxy interviewing. The incidence of elder abuse reported by the New York study was quite high, 7.6% for any form of abuse in the previous year. The report also included a study that reviewed documented case data in addition to the telephone survey. The documented case data found that the largest group of perpetrators across all abuse types were adult children (39.7%) whereas the telephone survey found that adult children (19.63%) were a slightly smaller group than spouse/partners (28.37%).

Elder Abuse and Neglect in Ireland (the Irish study)

The most recent study examined was the Irish study (Naughton et al., 2012). The study was considered robust by the member researchers owing in part to its solid sampling methodology; the researchers used a multi-stage cluster random probability sample with quota controls for age and gender. The survey used a shorter list of measures than the ABUEL and the UK study and covered socio-economic and demographic details, health (using the SF8), social support (using the Oslon-3), as well as the abuse measures, slightly modified, from the UK study. With a sample size target of 2000 it was estimated that they could estimate within 1% of true prevalence. The resulting prevalence was 2.2% for any abuse for the previous year. Of particular interest to the EAPU was that many of the results are consistent with Helpline data. For example people 80 years and over were reported to experience the most abuse, and EAPU Helpline data consistently indicates that the largest age group of victims is the 80-84 year age bracket. Similarly, in Ireland adult children were reported as the largest group of perpetrators (50%), followed by other relatives (24%), then spouse/partners (20%) again this pattern is similar to EAPU Helpline data.

The Irish study’s measure of abuse closely matched the UK’s measure but there were a number of modifications: it reduced the sexual abuse measure to three items from six. Increased the financial abuse items from eight to nine by including “Stopped contributing to household expenses such as rent or food where this had been previously agreed”. Reduced the physical abuse measures to nine items from 11, increased psychological abuse to seven items from six by including “Removed or prevented you access to equipment such as hearing or walking aids.” The opinion of the EAPU is that these modifications were positive; the failure to contribute to household expenses, and withholding access to aids that assist independence, are commonly heard on the Helpline. Overall the EAPU sees the operational definitions used by the Irish study as both concise and most consistent with the abuse situations the unit encounters.

European Abuse and Violence against Older Women, “Violation of personal rights” items

In addition to the elder abuse studies the subgroup discussed the inclusion of a measure of violations of personal rights which was identified in a paper on the European Abuse and Violence against Older Women (AVOW) study (De Donder et al., 2013). The AVOW also uses an adapted CTS2, but unlike the previous studies examined, it includes a set of questions on the violation of personal rights. This set includes: hindering in personal decisions, hindering from reading mail, hindering to take part in activities, and hindering from meeting friends. Unlike for younger able people where such items seem to clearly indicate power and control issues, things such as reading mail and making personal decisions for a person are commonly viewed as ‘helpful’ activities when applied to

older members of family. The key factor is the older person's perception of 'hindering' in these items. Although not conclusively abuse, the items resonate with 'red flags' that trigger concerns of the callers to the Helpline. In particular these items resonate with the observations of concerned others where an older person may be not acknowledging or conceptualising another's behaviour as abuse. The EAPU sees these items as potentially offering an indicator of 'hidden abuse' and although no claims could be made as such, they would seem to offer a litmus test for the level of respect for older people's autonomy in Queensland. Interest in including these measures is primarily the EAPU's, but there was no objection from subgroup members.

Additional measures for a Queensland prevalence study

Overall, the subgroup sees the Irish study as a good base for a Queensland prevalence study. It draws upon the extensive work done on the operational definitions in the UK study and includes a moderate amount of validated health and social support questions. Key requirements for the subgroup include substantially more information regarding the demographic and socio-economic status of perpetrators who are family, partners, friends-as-family or informal carers. It is a priority to ensure that sufficient demographic and socio-economic details are obtained about victims and perpetrators to enable matching with larger data-sets such as the Survey of Disability Ageing and Carers and General Social Survey. Also, relationship factors in the international studies were found to be too limited for the subgroup and at a minimum members would like to see items indicating: the perpetrators possession of an Enduring Power of Attorney for the victim; being a recipient of a government carers payment or allowance for the victim; being a Centrelink nominee for the victim; or being a health attorney for the victim. EAPU would also like to see a measure of duration of the abuse occurring within each relationship, and length of relationship where the abuser is a spouse or friend.

The subgroup had no specific requirements, with the exception of the WHO quality of life survey, as to which additional measures should be included in the survey; only that the measures were valid and maximise national and international comparability. However, it was commented that for disability measures (and consequently the neglect measure) the International Classification of Functioning (ICF) framework would be a desirable alternative to the Activities of Daily Living measures commonly used in other studies.

The EAPU also sees the inclusion of questions about interventions as desirable, that is to measure if assistance was sought, how and from who (i.e. family, legal, social work), and how effective the intervention was.

Where to from here?

The EAPU Reference Group Research Subgroup has provided valuable input into this 'wishlist' for a prevalence study that would ensure that an elder abuse prevalence study would be useful to service level stakeholders in Queensland. Any such endeavour would require the development of a research proposal by a suitably qualified academic researcher in addition to the sourcing of significant funding. As identified by the subgroup, the biggest challenge to a prevalence study is securing funding. The EAPU submits this document to the EAPU reference group for further discussion on the prospect of identifying and securing funding opportunities for a Queensland prevalence study.

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Appendix 1