Elder Abuse Prevention Unit

EAPU Reference Group Research Subgroup – Final Summary

A 'wishlist' for a prevalence study

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 facilitates 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 dialing. 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

	UK	Ireland	New York	ABUEL
Financial	One or more instance of financial abuse in the past year by family member, close friend, care worker	One or more incidents in the past 12 months by family member, close friend, care worker	Catagorised for severity. Scored on frequency: 'never', 'once',' 2-10 times', '11+ times'; and on self-report severity or impact: 'not at all serious', 'somewhat serious', 'very serious', All high severity items were included as abuse, moderate severity items were included when they had occured 11+ times in the past year and were considered very serious by the	Catagorised for severity. Scored on frequency 'once', 'twice', '3-5 times', '6-10 times', '11-20 times', or '>20 times' during the past year, or, 'did not occur the past year but before', or 'never occurred'. Items were rated for severity but inclusion criteria not specified.
	Stolen money, possessions or property	*Stolen money or any of your possessions/property/land or documents*	High: *Stolen anything from you or used things that belonged to you but without your knowledge or permission? This could include money, bank ATM or credit cards, cheques, personal property or documents.*	High: *Someone stole or used items without permission*
	Attempted to steal money, possessions or property	*Deliberately prevented you access to your money/possessions/property/land or documents*	High: *Forced, convinced or misled you to give them something that belonged to you or to give them the legal rights to some-thing that belonged to you? This could include money, a bank account, a credit card, a deed to a house, personal property, or documents such as a will (last will/testament) or power of attorney.*	High: *Forced or misled you to give away something that belonged to you*
	Made you give money, possessions or property	*Forced or misled you into giving them money/possessions/property/land or your pension book against your will*	High: *Pretended to be you to obtain goods or money?*	High: *Pretended to be you to get goods or money*
	Tried to make you give money, possessions or property	*Forced or misled you to sign over ownership of your home or property or pension book against your will*	Moderate: *Stopped contributing to household expenses such as rent or food where this arrangement had been previously agreed to, even if they were capable of still doing so?*	Moderate: *Stopped contributing to household finances*
	Used fraud to take money, possessions or property	*Forced or misled you to change your will (Last Will/Testament) or any other financial documents against your will*	Moderate: *Unwilling to contribute to household expenses to the extent that there was not enough money for food or other necessities?*	Moderate: *Unwilling to contribute to household expenses*
	Tried to use fraud to take money, possessions or property	*Signed your name on cheque/pension book or other financial documents without your knowledge or permission*		
	Taken or kept power of attorney	*Misused the power of attorney you gave them or have been forced, convinced or misled into signing a power of attorney*		

	Tried to take or keep power of attorney	*Tried/pressured you (but not succeeded) in doing any of the previous (to steal money, property, change legal documents)*			
	**Non payment of rent/bills by family/friend*	*Stopped contributing to household expenses such as rent or food where this had been previously agreed*			
	UK	Ireland	New York		ABUEL
Physical	One or more instance of physical abuse in the past year by family member, close friend, care worker	One or more incidents of physical abuse in the past 12 months by family member, close friend, care worker	Elder Mistreatment'	One 'elder mistreatment' instrument covering physical, psychological and sexual abuse. Scored on frequency: 'never', 'once',' 2-10 times', '11+ times'; and on self-report severity or impact: 'not at all serious'. Any endorsement of or sexual abuse physical abuse items was included. Psychological abuse items were included when they had occurred 11+ times in the past year or where the impact was considered very serious by the respondent.	Scored on frequency 'once', 'twice', '3-5 times', '6-10 times', '11-20 times', or '>20 times' during the past year, or, 'did not occur the past year but before', or 'never occurred'. Inclusion criteria not specified.
	Slapped you	*Tried to slap or hit you*		*Thrown something at you?*	*Tried to slap or hit you*
	Grabbed, pushed or shoved you	*Pushed, grabbed, shoved or slapped you*		*Tried to slap or hit you?*	*Pushed or grabbed you*
	Kicked, bit or hit you with a fist	*Kicked, bit or hit you with a fist*		*Pushed, grabbed or shoved you?*	*Slapped you*
	Burned or scalded you	*Hit or tried to hit you with an object*		*Slapped you?*	*Kicked, hit, or bit you with a fist*
	Threatened you with a knife, gun or other weapon	*Burned or scalded you*		*Kicked, bit or hit you with a fist?*	*Tried to hit you with something else*
	Used a knife, gun or other weapon	*Given you drugs or too much medicine in order to control you or make you sleepy*		*Hit or tried to hit you with something?*	*Locked you in a room*
	Any other violence	*Restrained you in any way e.g. locked you in your room, tied you in a chair*		*Locked you in your room?*	*Beat you up*
	Tied you down	*Threatened you with a knife, gun or other weapon*		*Beat you up?*	*Threatened you with a knife or gun*
	Locked you in your room	*Injured you with a knife, gun or other weapon*		*Threatened you with a knife or gun?*	*Thrown something at you*
	Given you drugs or too much medicine in order to control you/ to make you docile			*Used a knife or gun?*	*Used a knife or gun against you*
	Restrained you in any other way			*Has anyone done anything violent to you that you have not mentioned?*	*Committed other violence against you*

	UK	Ireland		New York	ABUEL
Sexual	1 or more instance of sexual harassment / abuse in the past year by family member, close friend, care worker	One or more incidents in the past 12 months by family member, close friend, care worker.			Scored on frequency 'once', 'twice', '3-5 times', '6-10 times', '11-20 times', or '>20 times' during the past year, or, 'did not occur the past year but before', or 'never occurred'. Inclusion criteria not specified.
	Talked to you in a sexual way that made you feel uncomfortable	*Talked to you in a sexual way that you did not like*			
	Touched you in a sexual way against your will	*Touched you or tried to touch you in a sexual way you did not like/ against your will*		*Touched you or tried to touch you in a sexual way against your will?*	*talked to you in a sexual way*
	Tried to touch you in a sexual way against your will	*Forced you or tried to force you to have sexual intercourse against your will*		*Forced you to have sexual inter-course against your will?*	*Touched you in a sexual way against your will*
	Made you watch pornography against your will				*Tried to touch you in a sexual way against your will*
	Tried to make you watch pornography against your will				*Had sexual intercourse with you against your will*
	Had sexual intercourse with you against your will				*Made you watch pornography against your will*
	Tried to have sexual intercourse with you against your will				*Tried to make you watch pornography against your will*
					Tried to have sexual intercourse with you against your will
					Other serious molesting behaviours
	UK	Ireland		New York	ABUEL
Psychological	10 or more instances of psychological abuse in the past year by the same person (family member, close friend, care worker)	Ten or more incidents of psychological abuse in the past 12 months by family member, close friend, care worker, and /or <10 instances if the abuse had a serious impact			Scored on frequency 'once', 'twice', '3-5 times', '6-10 times', '11-20 times', or '>20 times' during the past year, or, 'did not occur the past year but before', or 'never occurred'. Inclusion criteria not specified.
	Insulted you, called you names or sworn at you	*Insulted you, called you names or swore at you*		*Insulted or sworn at you?*	*Insulted or sworn at you?*
	Threatened you	*Threatened you verbally*		*Threatened to hit or throw something at you?*	*Threatened you (e.g. putting you in a nursing home. Breaking things that you care about)*
	Undermined or belittled what you do	*Undermined or belittled what you do*		*Additional items. Not referred to in report:*	*Undermined or belittled you*
	Excluded you or repeatedly ignored you	*Excluded you or repeatedly ignored you*		*Sulked or refused to talk about something?*	*Excluded you or repeatedly ignored you*

Elder Mistreatment'

Psychological	*Threatened to harm others that you care about*	*Threatened to harm others that you care about*	Elder Mistreatment'	*Threatened to harm others that you care about (e.g. pets, relatives)*
	Prevented you from seeing others that you care about	*Prevented you from seeing others that you care about or your doctor or nurse*	*Done or said something to spite you?*	*Prevented you from seeing others that you care about*
		Removed or prevented you access to equipment such as hearing or walking aids		*shouted or yelled at you*
				Did something to spite you
				Called you fat, ugly or other names
				Destroyed something that belonged to you
				Threatened to hit or to through something at you
	UK	Ireland	New York	ABUEL
Neglect	10 or more instances of neglect in the past year by family member, close friend, care worker OR less than 10 instances in the past year but judged by the respondent to be "very serious".	Neglect is based on an assessment of a person's ability to independently perform basic and complex activities of daily living. Neglect was identified if a person:	An ADL or IADL was deemed to be neglected when the negelct occurred more than 10 times in the previous year, and/or the particiant described the neglect as being somehat or very serious for them. Based on the Duke OARS_IADL and Duke ADL.	Neglect was assesed with 13 items where the participants were asked whether they needed help and received it, needed help but did not receive it or did not need help.Inclusion criteria not specified in report.
	Respondent must have stated that they need and receive help with an activity, and that they have difficulty carrying out the activity by themselves.	(i) Stated they were unable to perform an activity independently. (ii) Had experienced refusal by a carer to supply help more than 10 times in past 12 months OR	IADL Neglect: Failure of designated/responsible caregiver to assist with: shopping; assist with meal preparation; housework, medical administration	*Shopping groceries, clothes or other things.*
	Neglect grouped into three categories: 1. Day to day activities (shopping for groceries or clothes, preparing meals, doing routine housework, travel or transport) 2. Personal care (getting in and out of bed, washing or bathing, dressing or undressing, eating including cutting up food, getting to and using toilet) 3. Help with correct dose and timing of medication	(iii) Not receiving the help was perceived by the older person as having a serious impact on them Complex activities of daily living are list as: shopping for food clothes, preparing food, housework, taking medication, using public transport or driving Basic activities of daily living are defined as cutting up and eating own food, moving around the house, going to the toilet, dressing, washing	ADL Neglect: Failure of designated/responsible caregiver to assist with: feeding; ambulation transfers; bathing; toileting; any specific task.	*Preparing meals* *Doing routine housework* *Getting in and out of bed* *Wasing or bathing (including getting in and out of bath or shower)* *Travel or transport* *Dressing or undressing* *Eating, including cutting up food* *Getting to and using toilet* *Help with correct dose and timing of medication* *Any other day-to-day activity (specify)* *Other hosehold activities (eg gardening)* *General mobility in the house/careing-home*

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Research

Enduring Powers of Attorney: Promoting attorneys' accountability as substitute decision makers

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Aim: *The misuse and abuse of Enduring Powers of Attorney (EPAs) by attorneys, particularly in relation to financial decision-making, is a growing concern. This paper explores the opportunities to enhance accountability of attorneys at the time of the execution of the document in Queensland.*
Method: *A four-stage multi-method design comprised a critical reference group; semi-structured interviews with 32 principals or potential principals, attorneys and witnesses; two focus groups with service providers and a state-wide survey of 76 principals, attorneys and witnesses.*
Results: *Across all methods and user groups, understanding the role and obligations of the attorney in an EPA was consistently identified as problematic.*
Conclusions: *Promoting accountability and understanding can be addressed by greater attention to the role of the attorney in the forms/ guidelines and in the structure and witnessing of the forms, increased direction about record keeping and access to appropriate advice and support.*

Key words: *enduring powers of attorney, substitute decision making.*

Introduction

Policy interest in planning for later life decision-making has been driven by the need to provide for an extended period of older age and the potential for impairment in decision-making capacity in late old age. In response, many countries introduced legislation to provide for substitute decision makers in the event of incapacity. Such legal documents allow for a person with capacity (a principal or a donor) to nominate a substitute decision maker(s) (an attorney, agent or donee) to make personal/health and financial decisions if they are unable to make such decisions themselves. These documents vary in terminology (enduring or durable powers of attorney, advance directives, lasting powers of attorney or enduring guardianship) and whether if one document covers one or all domains.

Enduring powers of attorney (EPAs) are widely promoted as an accessible and affordable mechanism for substitute decision-making that can be completed, in many jurisdictions, in the absence of legal advice. The initial emphasis was commonly on simplicity, flexibility, convenience, ease of execution and accessibility. Over the past decade, striking a balance between ease of use and protection has been a growing concern. Concerns arise from the level of understanding of the documents and the powers they confer; the amount of protection provided for principals, particularly in relation to financial decision-making; limited understanding of the nature of decision-specific capacity assessment and inappropriate use of substituted decision makers when an individual has capacity to make a specific decision [1–4].

The most common critique of current practice relates to the misuse and abuse of EPAs by attorneys resulting from the breadth of financial powers conferred by the instruments combined with limited accountability and independent monitoring of attorneys [5–8]. Dessin [5] also highlights the lack of clarity of the role of attorney/agent, calling it 'unscripted'. Australian research demonstrates that financial abuse is contingent upon access to assets. EPAs provide such access [9].

Concerns about the failure to protect principals or safeguard vulnerable people have driven recent legislative changes in the United Kingdom [10] and the United States [8]. Such reforms have sought to enhance protection through changes in three main areas: (i) changing the requirements for executing an EPA by increasing notarisation requirements, the number of witnesses or introducing a registration system [11]; (ii) clarifying limitations on an attorney's authority or putting in new limitations around gift giving and self-dealing; and (iii) enhancing education, support and the ability of third parties to monitor EPA relationships [7,8,11]. Such changes have been applauded as providing greater safeguards for principals [8] and criticised for reducing accessibility by increasing cost and complexity [7].

Queensland context

Australian substitute decision-making legislation is state and territory based. Although there are differences in terminology, processes for execution of documents and adult protection systems, all have a form of financial EPA. In Queensland, under the *Powers of Attorney Act* 1998, an EPA can be

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executed for financial and personal/health decisions. In addition, an advance health directive (AHD) can also be completed. Under an EPA, one or multiple attorneys and different attorneys for different domains (financial, personal/health) can be appointed. The document can be executed without a lawyer. Forms are available on line and kits can be purchased from newsagents. The EPA, however, does have to be witnessed by a lawyer, a Justice of the Peace (JP) or a Commissioner for Declarations. The attorney's signature is not required at the time of execution and is not witnessed. There is no general registry for EPAs and there is no ongoing monitoring of an attorney, but registration is mandatory to deal with land. It is thus impossible to know how many EPAs are activated in the state. An EPA can include special conditions to limit the power (e.g. conditions about gifts, sale of property). Where a person has impaired capacity, concerns about the actions of an attorney can be brought to a tribunal.

Recent reviews and research [12,13] in relation to EPAs explored the best way to access, execute and use the information and forms appropriately. Our research arose from concerns of government, service providers, researchers and legal and health practitioners about the level of understanding, knowledge and use of EPAs and AHDs in Queensland. The interdisciplinary project examined barriers to uptake for both EPAs and AHDs, the content and usability of these forms and the processes and practices surrounding the execution and use of the documents. This paper focuses on the role of attorneys, particularly as financial decision makers, and opportunities to enhance accountability at the time of the execution of an EPA in Queensland. Although the research canvassed views on the role of attorneys as personal/health and financial decision makers, this paper focuses on financial decision-making as the domain consistently highlighted as the most problematic in relation to accountability.

Methods

The four-stage mixed-method design included a wide range of user and potential user groups. The purposive sampling strategy included (i) consumer groups – people who have used or might use the form as principals or attorneys and (ii) professionals (social workers, legal practitioners), service providers and witnesses. Outreach to Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds (CALD) ensured a range of perspectives were considered. The research design comprised:

1. A Critical Reference Group (medical, social work, legal practitioners and advocacy and guardianship representatives) which provided expert input and reviewed research tools.
2. Semi-structured interviews with 21 principals, attorneys, potential principals, witnesses and guardianship staff. In addition, 11 Indigenous Australians (from Murri and Torres Strait Islander Groups) were interviewed by an indigenous researcher. The questions covered motivations and intentions in having an EPA, experiences with EPAs, capacity assessment, understanding by principals and attorneys of the powers and obligations being conferred, use and usability of the forms and the information provided and record keeping. All respondents had access to the relevant forms during the interview to facilitate specific feedback. Principals and attorneys who had completed an EPA were recruited through advertising in newsletters, websites, local community newspapers and University data bases. Professionals and witnesses with specialised knowledge about the use of the forms were recruited through professional networks and the Critical Reference Group members.
3. Online surveys distributed to principals, attorneys and witnesses across Queensland using a web-based survey tool. Copies of the EPA forms were attached so that respondents had the opportunity to consult the forms as they completed the survey. The surveys were distributed through e-newsletters, a broad range of organisations, professional networks, a consumer health forum and a regional forum on later life decision-making hosted by the Public Trustee of Queensland. The survey questions and Likert scales were developed from issues raised in the Stage 2 interviews. A total of 76 surveys relating to EPA forms were returned, 30 from principals, 23 from attorneys and 23 from witnesses with experience of EPAs. The sample is generally of well-educated users of the documents with an overrepresentation of tertiary education for principals and attorneys. Although there is a broad age range, there is also an overrepresentation of women, people born in Australia and with English as the first language. No Aboriginal or Torres Strait Islander person completed the survey as a principal; one attorney identified as Aboriginal or Torres Strait Islander. Thirty-five percent of principals and 44.5% of attorneys were from regional areas.
4. Two focus groups were held with practitioners in relation to their experiences, knowledge and use of EPAs: workers with CALD groups (15 participants) and social workers in health settings (eight participants).

The semi-structured interviews and focus group discussions were audio recorded, transcribed and analysed thematically. Descriptive statistics reported on patterns and trends in the survey data. The research had human ethics approval from The University of Queensland (No. 2009001660).

The purposive sample is not representative, probably attracting people with strong opinions about their experience of EPAs. The multi-method approach did, however, include a diversity of user groups. Although the survey sample of principals and attorneys primarily comprises people who are least likely to have difficulties in reading the form, problems they identify in understanding the forms, processes and practices are likely to be much greater for those in the population with more limited education and English language skills.

Results

Overall, the EPA was generally evaluated as working well for people as principals, witnesses and attorneys who are well

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informed about the purpose and operation of EPAs. However, some principals and attorneys are less informed about the powers and duties conferred. Additionally, some groups in the community, notably CALD and indigenous peoples, are less likely to be well informed about the EPA.

The most striking finding of the study is that across user groups and across all methods of data collection, the role of the attorney in an EPA was consistently identified as problematic. Principals, attorneys, witnesses and professionals/service providers all noted that aspects of the form, the information provided and processes in place at the time of executing the document do not necessarily assist attorneys and principals to fully understand the role and responsibilities of attorneys. Key issues identified included understanding the powers and obligations conferred by an EPA, clarity of record keeping obligations of an attorney and the use of terms or conditions to provide further direction to attorneys or restrict their powers.

Understanding powers and obligations

The principals' understanding of the powers being conferred varied considerably. Some had a very detailed understanding; others simply relied on the attorney to 'do the right thing'. Although some witnesses (e.g. lawyers and JPs) had a very careful process to ensure the principal understood the power being conferred, others took a more routine approach to witnessing the document.

Overall, respondents reported that the principal was responsible for ensuring the attorney understood the nature and scope of the powers and their role and obligations. Attorneys, however, generally reported that they did not have their responsibilities outlined to them by the principal or any intermediary who helped the principal draw up the form.

> [The form] is very useful; but it didn't stress, once again, perhaps the limits of being an attorney, and the duties and the responsibilities. [EPA Interview 18]

Attorneys reported they needed more information on how to make decisions, keep records, activate and terminate their role and where to go for advice. Some were concerned about their understanding of the commitment they were undertaking.

> For the attorney, I'm not sure that they fully understand that they are held accountable and that they could be involved in acting legally for the person. I think they understand the concept of paying the bills, but I'm not sure that they really understand that they are the legal representative and would be involved in any difficult or conflictual arrangements. [EPA Interview 7]

Overall, witnesses were concerned that principals did not completely understand a number of important issues relating to activation and termination, capacity and the use of special terms or conditions. Witnesses also considered that attorneys did not always understand what the powers and associated responsibilities were.

> [T]he main issues are that the attorney doesn't understand their responsibility and they think it's just a piece of paper that Mum or Dad wrote to give them the ability to manage their affairs or manage their health if they want to but they don't have to do it if they don't want to. . . . There's a small proportion that manipulate their form but the majority of people I think it is a lack of understanding of their obligation. [EPA Interview 16]
>
> I get a sense a bit that (principals are told) 'oh your attorney has to do these things, don't worry about that. Just appoint someone without getting into too much details'. [EPA Interview 4]

One respondent put an alternative view:

> I think if they [attorneys] read it there would be less misconduct. So that's no excuse. The form does what it needs to do to tell attorneys what their responsibilities are as opposed to other states' forms that don't, within the form. [EPA Interview 3]

This suggests that some of the issues for attorneys could be resolved if parties carefully read the form and are engaged in the processes surrounding the execution of the document. However, most groups reported problems with the information provided, the language and structure of the form itself and the practices surrounding the execution of the document.

The survey also demonstrates there are problems in ensuring that attorneys understood their role. In response to Likert scales seeking comment on the adequacy of the explanation of the role and obligations of an attorney in the form and the guidelines, 52% of principals agreed that it was adequate. Attorneys were much less sure, only 25% of attorneys agreed that the explanations were adequate. In addition, only 24% of attorneys agreed they were adequately alerted to the serious nature of their appointment as an attorney.

What was missing was reported to be descriptions and explanation about activation of the EPA, timelines and expenses; worst case scenarios – 'at present the forms assumes everything will go smoothly in families'; 'how to do the role' – make decisions and keep records; explanations about when it commences, how to make decisions about capacity for a matter, an explanation of the advocacy role of an attorney, or what happens if the attorney abuses power.

Record keeping

The obligation to keep records is core to accountability for financial decision-making. Although the form clearly indicates a responsibility to keep records, limited understanding of how to enact this responsibility and the implications of

inadequate recording keeping were consistently reported across principals, attorneys, service providers and witnesses.

An attorney with a background in the finance industry reported that when he started to act as an attorney, he reread the document and said, 'one of the things it really highlighted for me was you must keep records'. However, he was unable to find guidelines on what records to keep. Another attorney, with much less background in managing other people's money, agreed:

> There should be more guidance given to attorneys on what records to keep and how to keep them. [EPA Interview 14]

In addition, she added that there should be much more warning given to attorneys on what might happen if abuse occurs, or they do not meet their obligations.

From the survey, most principals (85%) and attorneys (94%) agreed that more information was needed on the responsibility to keep records. Attorneys also wanted more information on gifts and conflicts of interest (100%) and when the Office of the Adult Guardian will investigate (94%).

Use of conditions to limit attorneys' authority

Putting conditions or limitations on an attorney's authority to act can provide direction for attorneys and thus enhance accountability. The interviews revealed that most people did not use special conditions. This was attributed to a lack of understanding of what could be included, the design of the current form which actively discourages the use of conditions and the information provided. It also reflects a view of most principals outlined by one respondent:

> I did not set any conditions or read any information about setting conditions or potential abuse because I trust my attorneys. [EPA interview 12]

In the survey, most principals (66%) reported that they did not use special conditions, but the vast majority of principals (92%) wanted more information on how to include special conditions to add specific additional powers; while 80% wanted more information on how to restrict powers in relation to gifts, conflicts of interest, consulting with others, annual accounting and preventing some decisions about property. Findings suggest that the value of principals and attorneys having greater knowledge of how, when and whether to include conditions should be recognised, although this may restrict the ease of use of EPAs.

Discussion

Under ideal conditions, EPAs enhance autonomy by allowing principals to select agents to act on their behalf if decision-making capacity becomes impaired [7]. In many cases these documents work well. A major critique of EPAs, however, relates to the accountability of attorneys. Accountability depends upon them being informed of their roles and responsibilities, aware of the principal's intentions, having the motivation and skills for the tasks and the capacity to undertake the complex roles of substitute and supported decision maker and prudent asset manager and record keeper.

In Queensland, in Dessin's [5] term, there is a 'script'. There is considerable information in forms and guidelines about the role and responsibilities of attorneys. However, this does not mean that, at the time of execution, the attorney understands them. To improve accountability, education and support targeting the role of attorneys is a priority. This could include an extensive targeted information booklet, DVDs and case scenarios for attorneys, the provision of examples of record keeping and access to advice and assistance at the time of execution and when acting an ongoing decision maker.

Current practice allows for documents to be executed in the absence of the attorney. Executing an EPA as part of routine estate and financial planning runs the risk of paying insufficient attention to the serious nature of the appointment and role of the attorney. For some there was insufficient definition of the role and discussion of the seriousness of the appointment. In the research, there was little evidence of a collaborative process that involved the principal and attorney in discussion of powers, intentions, role and responsibilities. Kohn [11] has noted that establishing a collaborative relationship should enable the agent to make better decisions on behalf of the principal in the event that the principal becomes incapacitated. It also encourages communication between the principal and the attorney, which is at the heart of any substitute decision-making. Greater inclusion of attorneys in the processes at the time of execution of the document is vital to setting this up.

The obligations of attorneys need to be further highlighted in the structure and witnessing of the forms. Attorneys and principals should be required to read all parts of the document and indicate their understanding of the scope, nature and obligations of the power being conferred. Witnessing of their signatures would also highlight the importance of the role.

Conclusion

Carney [14] has noted that that an enduring power is only as good as the agent is trustworthy and willing to accept responsibility. The authors would add to this, the importance of the attorney understanding their responsibility and being capable of carrying out the tasks. In promoting changes to information, documents and processes, the tensions between accessibility/flexibility and appropriate use and protection need to be considered. As many jurisdictions contemplate enhancing protection through registration and/or increased monitoring of attorneys, it is timely to also consider what actions can be taken at the point of execution to improve protections for attorneys and principals, particularly in the area of financial decision-making.

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Key Points

- EPAs have been widely promoted for substitute decision-making.
- Misuse and abuse of decision-making powers by attorneys are increasingly recognised.
- Attorneys often accept appointment without understanding their role and obligations.
- Access to information, advice and support at the time of execution of the EPA and when the document is activated is vital to promote accountability of and understanding by attorneys.

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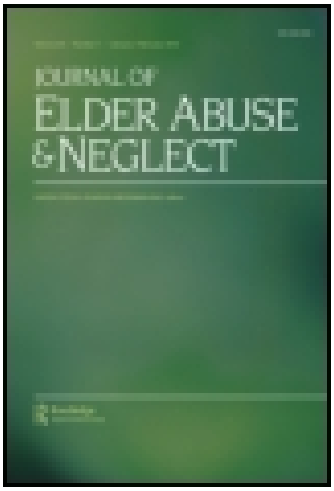

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Individual and Community Attitudes Toward Financial Elder Abuse

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Individual and Community Attitudes Toward Financial Elder Abuse

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This study investigated attitudes toward financial elder abuse by sections of the Australian community using three focus groups, including Aged Care Workers, Older Adults, and Younger Adults. Participants were provided discussion cues prior to their focus group (i.e., What is financially abusive behavior? Why does it occur? How can it be prevented?). Two researchers authenticated the transcripts and identified micro- and macro-level themes within and across the groups. The study revealed a range of similar, different, and individual attitudes expressed across the groups, which could be used to develop a survey for a broader investigation of the role of individual attitudes and social/cultural norms in financial elder abuse.

KEYWORDS attitude, financial elder abuse, qualitative

Financial elder abuse, also referred to as "financial exploitation," "financial mistreatment," "economic abuse," or "material abuse," has many definitions, all with the underlying theme of illegal or improper use of an elder's assets (Boldy, Horner, Crouchley, Davey, & Boylen, 2005; Comijs, Pot, Smit, Bouter, & Jonker, 1998; Dessin, 2000). Some definitions distinguish criminal activity, like theft and fraud, from financial abuse by stating that financial abuse tends to occur within trusting relationships (State Government of Victoria, 2006), thereby excluding institutions and strangers as possible perpetrators of abuse. However, the World Health Organization and International Network for the Prevention of Elder Abuse (WHO & INPEA, 2002) have supported a broader definition not requiring a prerequisite of

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trust between the abused and abuser, defining financial elder abuse as "the illegal or improper exploitation or use of funds or other resources of the older person" (p. 126). This broader definition is adopted within the current study.

Financial elder abuse is possibly the fastest growing and most common form of elder abuse internationally (Bomba, 2006; Procopis, 2007), accounting for between 26% and 38% of all reported cases of abuse (Choi & Mayer, 2000; Malks, Buckmaster, & Cunningham, 2003; McCawley, Tilse, Wilson, Rosenman, & Setterlund, 2006; Procopis, 2007; Tatara et al., 1998). Victims tend to report experiencing more than one form of abuse at the same time, in particular psychological and financial abuse (Boldy, Webb, Horner, Davey, & Kingsley, 2002; Procopis, 2007). The international prevalence of financial elder abuse ranges between 1.3% and 5% depending on the definition of financial abuse and sampling method used by the researchers (Cooper, Selwood, & Livingston, 2008; Crosby, Clark, Hayes, Jones, & Lievesley, 2008; O'Keeffe et al., 2007). These figures likely represent an underestimate of the actual prevalence of financial elder abuse in the community, as the majority of victims are reluctant to report the abuse (Boldy et al., 2002; Tatara et al., 1998; for review see Lowndes, Darzins, Weiner, Owada, & Mihaljcic, 2009). Research has shown that family members are the most likely perpetrators of financial elder abuse (Boldy et al., 2005; O'Keeffe et al., 2007), in particular, adult children (Choi, Kulick, & Mayer, 1999; Procopis, 2007; Tatara et al., 1998). Many victims, therefore, may be reluctant to report being abused, as they do not want a family member to be prosecuted (Sklar, 2000), or they may feel some responsibility for the perpetrator's actions (Dessin, 2000). Furthermore, the elder may fear institutionalization and a withdrawal of social support from the abuser or other family members (e.g., grandchildren) if they report the abuse (Dessin, 2000; Rosenman, Wilson, Tilse, Morrison, & McCawley, 2006). Many victims are unaware the abuse is occurring (Dessin, 2000; Sklar, 2000; Tilse, Wilson, Setterlund, & Rosenman, 2005). Codependency with the abuser and social isolation are common environmental risk factors for financial elder abuse (O'Keeffe et al., 2007; Procopis, 2007).

There have been many preventative and intervention strategies suggested to reduce financial elder abuse (for review see Lowndes et al., 2009). Examples include raising awareness of the risk of abuse in the elderly community, encouraging social connectedness of elders, training professionals to detect and manage suspected abuse, closer monitoring of individuals' bank transaction patterns, introducing legal penalties to deter potential abusers, introducing mandatory reporting of suspected abuse, and encouraging formal mechanisms for elders to protect their finances through the use of financial trusts, bonds, or the appointment of Enduring Powers of Attorney (EPA; Anetzberger, 2001; Dessin, 2000; Langan & Means, 1996; Malks et al., 2003; Murray & Jacoby, 2002; Rabiner, Brown, & O'Keeffe, 2004; Reed, 2005;

Setterlund, Tilse, & Wilson, 2002; Swan, 2007; Tilse, Setterlund, Wilson, & Rosenman, 2005; Tilse et al., 2005). While many have been trialed around the world, few have been formally evaluated in terms of their time and cost effectiveness in reducing the local incidence of abuse, and there is a dearth of research comparing the effectiveness of one strategy against another (Lowndes et al., 2009).

Theoretical or conceptual models of elder abuse highlight the complex interaction of risk factors for abuse occurring at the level of the individual (i.e., abuser and victim) and environment (i.e., situational factors; for review see Anetzberger, 2005). Conceptual models of elder abuse by both Schiamberg and Gans (2000) and Rabiner, O'Keeffe, and Brown (2004) highlight the important influence of societal or "macrolevel" factors, such as societal attitudes, cultural norms, local policy, and legislation. Both models imply that financially abusive behavior may be defined to some extent by an individual's personal belief system or attitudes, as well as the shared belief system or attitudes existing within a specific community or culture. Understanding of individual and community attitudes is important in terms of its potential to explain the context in which financial abuse occurs, as well as to explain variations in rates of detection and reporting, and acceptance of different interventions and punishments. Both individual and social attitudes are widely understood to influence an individual's behavior. For example, Ajzen's empirically-supported "Theory of Planned Behavior" (TPB) explains that an individual's "perceived behavioral control" (perception of one's own control over the situation), "subjective norms" (perceived pressure from significant others to perform the behavior), and "individual attitudes" (toward the behavior and the subject) are important predictors of a person's intention to act, which in turn significantly predicts the individual's behavior (Ajzen, 1991; Armitage & Conner, 2001; Glasman & Albarracin, 2006). In terms of social norms, a review by Smith and Louis (2009) on attitude-behavior relations demonstrated that social influence (i.e., perceived pressure from others to perform or not perform an act) can affect a person's attitudes and subsequent behavior, and this relationship can be strengthened by either increasing the individual's affinity with the group and/or their belief that the attitude/behavior is supported or unsupported by the group. Research also suggests that attitude change can be influenced by factors such as the persuasiveness of the message to change one's perception or attitude; the status, credibility, and attractiveness of the source of this message; and how the message is framed (Petty, Wegener, & Fabrigar, 1997; Vaughan & Hogg, 2005; Wood, 2000). These theories intrinsic in social psychology literature could be used to develop more effective prevention and intervention campaigns against financial abuse by changing people's attitudes that may be precipitating financial elder abuse in the community, or the failure to report it.

Research investigating attitudes and perceptions toward financial elder abuse often has done so in the context of general elder abuse research.

For example, elder abuse studies tend to contain only a small number of items relating specifically to financial abuse, and therefore their results should be interpreted cautiously. On this background, various studies do suggest that there are different cultural, social, familial, and generational expectations and attitudes about appropriate financial transactions within families (Anetzberger, Korbin, & Tomita, 1996; Daskalopoulos, Kakouros, & Stathopoulou, 2007; Daskalopoulos, Mullin, Donovan, & Suzuki, 2006; Helmes & Cuevas, 2007; Hudson & Carlson, 1998; Mercurio & Nyborn, 2006; Moon, Tomita, & Jung-Kamei, 2001; Moon & Williams, 1993; Sanchez, 1996; Tsukada, Saito, & Tatara, 2001).

In 2007, one of the biggest studies of community attitudes toward elder abuse was conducted in Western Australia using a semistructured telephone survey ($n = 801$; D'Aurizio, 2007). Among the questions, participants were asked to describe forms of elder abuse. Although previous research indicates financial/material abuse is the most common form, physical and psychological abuse were mentioned most frequently by participants in this study (27% and 24%, respectively, of sample), and financial/material abuse was the fourth most frequently mentioned (10% of sample). Two thirds of the sample believed financial EPAs were an effective mechanism for protecting an elder from financial abuse or exploitation. Daughters (40%) and sons (34%) were the most common people nominated as EPAs by people aged over 50 years in the sample. However, nearly two thirds of the sample reported that older people cannot always trust their children to act in their best interest, and a third believed sons and daughters were most likely to be perpetrators of financial elder abuse. Participants were asked to rate how seriously they considered a series of behaviors, including a number of finance-related behaviors. The overwhelming majority rated as "extremely serious": pressuring an older person to withdraw money from their bank account against their will and receiving a government benefit to care for an older person and not providing care. However, only half the participants considered it "extremely serious" if a family member, friend, or carer insisted on living with an older person but did not pay for accommodation or contribute toward bills, while approximately a quarter did not consider this as either "somewhat" or "extremely" serious. These results indicate that although there is general consensus in the community that certain behaviors are financially abusive, there is division about whether other behaviors are abusive. Finally, the overwhelming majority of the sample agreed that victims would be unlikely to seek outside help (93%) and that elder abuse should be reported to the police (96%). On this background, only 58% said they would definitely intervene.

There is very little research exploring individual and community attitudes specifically toward financial elder abuse, particularly research using qualitative research methods that provide the opportunity to collect rich and in-depth data. Therefore, the aim of this study was to investigate individual

and community attitudes toward financial elder abuse using three focus groups: one containing experienced Aged Care Workers, one containing Older Adults, and one containing Younger Adults. More specifically, we aimed to explore the attitudes shared across all groups, those that differed between specific groups, and attitudes unique to specific individuals within a group.

METHODS

Participants

Demographic details of each focus group sample are summarized in Table 1 (i.e., for Aged Care Workers, Older Adults, and Younger Adults). Seven people were included in each focus group as recommended by Krueger and Casey (2000) and Vaughn, Schumm and Sinagub (1996).

Aged Care Workers were recruited from a metropolitan Aged Person's Mental Health Community Team, Older Adults were recruited from a suburban University of the Third Age (U3A) center, and Younger Adults through Monash University, Clayton. Participants from each site were recruited by posters and information sheets.

Materials

Key discussion prompts were devised and are presented in Table 2. A handout of these prompts was distributed to participants via e-mail two to three days prior to the focus groups as recommended by Breen (2006), along with an explanatory statement and research consent form. An interview

TABLE 1 Demographics of Groups (Aged Care Workers, Older Adults, and Younger Adults)

	N (female)	Mean Age (*SD*)	Age Range	Mean Years Experience (*SD*)
Aged Care Workers	7(6)	52.17(7.44)	40–59	18.83 (9.04)
Older Adults	7(5)	69.14(7.86)	55–76	—
Younger Adults	7(6)	21.29(2.93)	18–26	—

TABLE 2 Key Questions Used to Stimulate Group Discussion

1. There are many definitions of elder financial abuse, and one of them is "illegal or improper use of an individual's assets." What do you consider to be "improper" use of an elder's assets?
2. Why do you think financial abuse occurs?
3. How do you think financial abuse could be reduced?
4. Do you think appointing a financial Enduring Power of Attorney (EPA) is a good strategy to reduce cases of financial abuse?

schedule was devised to ensure consistency by the group mediator across focus groups; the same researcher (TM) mediated each group, and a comediator was also present (GL). The schedule included an introductory statement, overview of the session, and general rules of the focus group, which assured and outlined limits to confidentiality and stated the aim of the discussion. Two tape recorders were used to record each focus group. Refreshments and name tags were distributed at each group, also as recommended by Breen (2006).

Procedure

Each focus group was organized at a time and place most convenient to the participants. After the moderator's introductory statements, participants provided written consent and basic demographic information (i.e., age, gender, and years of experience for the Aged Care Workers). The study received ethics approval by the Monash University Human Research Ethics Committee (MUHREC).

Focus group methodology outlined by Breen (2006) and Vaughn et al. (1996) was adopted; each focus group lasted approximately 60 min. Participants were seated at a round table to promote discussion. Before the commencement of the focus group, approximately 5 min was allocated to unstructured conversation in order to allow the participants time to relax and get to know each other. The focus groups were audio taped for later transcription. The moderator led the discussions while the comoderator assisted with practicalities (i.e., collecting consent forms, noting who was sitting where in relation to the recorders, and taking notes).

Qualitative Data Analysis

Thematic analysis was applied to the data. Thematic analysis is a method used for identifying, analyzing, and reporting patterns within qualitative data, and was chosen because it is a flexible research tool that can provide a detailed and complex account of data (Braun & Clarke, 2006). As individual and community attitudes toward financial elder abuse lack previous empirical research, thematic analysis was chosen as it provides a detailed description of the data without requiring an a priori theory on which the data analysis is based (Braun & Clarke, 2006).

Reliability, Validity, and Credibility of Analysis

Thematic analysis was conducted using an adapted version of that proposed by Braun and Clarke (2006; see Table 3), with adaptations aimed at enhancing the reliability and validity of the data. These included having a second

TABLE 3 Nine Steps Used to Conduct a Thematic Analysis

Step	Description
1. Familiarization with data	Transcribing data verbatim, verification of transcript, reading and rereading data, generating initial codes
2. Generating codes	Reading transcript, highlighting important quotes, generating codes
3. Grouping codes into themes	Combining codes into potential themes, gathering data relevant to theme
4. Reviewing themes	Checking that themes work in relation to extracts
5. Generating thematic map	Creating a visual representation of themes (subthemes and relationships)
6. Discussion with colleague	Discussing thematic map with colleague, comparing themes, and discussing themes
7. Generating a thematic map	Creating a visual representation of themes (subthemes and relationships) based on discussion and agreement between the two researchers
8. Comparing groups	Comparison of the three focus groups, discussing similarities and differences
9. Producing a report	Selection of vivid, compelling extract examples/quotes that relate to the research question

researcher (a) verifying the accuracy of the transcript, (b) generating thematic maps, and (c) discussing and verifying key emergent themes.

As one of the aims of this study was to explore a range of attitudes toward financial elder abuse, themes that strongly emerged across all three focus groups were identified (i.e., Similar Group Attitudes), as were strong themes emergent in only one or two groups (e.g., Different Group Attitudes). Finally, attitudes expressed strongly by an individual within a focus group, not necessarily consistent with the attitude of either their particular focus group or the other groups, also were identified (e.g., Individual Attitudes). The "keyness" of a theme was not only defined by quantifiable measures such as the frequency with which it was mentioned or duration of time spent discussing it, but how strongly participants felt about the issue as assessed qualitatively by the tone and nature of their comments, whether it captured something significant in relation to the overall research question, and whether it contributed to the aim of this study. Supporting evidence (quotes) for each theme are presented in the results section.

RESULTS

Similar Group Attitudes

Similarities in the attitudes of Aged Care Workers, Older Adults, and Younger Adults identified across the focus groups are presented below in Table 4.

The three groups expressed difficulty with defining financial elder abuse due to the complexity of the topic in general, often referring to the "grey

TABLE 4 Similarities Across Groups (Aged Care Workers, Older Adults, and Younger Adults)

The topic of elder abuse is complex.
Abuse behavior is difficult to define due to individual, family and cultural norms, and expectations.
Financial abuse includes the following: • using elders assets but not for their benefit • an action that results in a loss of security for the elder • not allowing the elder access to their assets • taking assets without consent • preserving the elders assets for own benefit • manipulation, coercion, or emotional pressure to separate an elder from their assets
Abuse occurs because • older people are vulnerable • abusers are greedy • abusers have a sense of entitlement due to underlying expectation of inheritance
More formal regulation is required to reduce abuse, including regulation of financial EPAs

areas" and "one of those difficult ones." When attempting to determine whether a behavior was financially abusive, all groups raised contextual issues as being important determinants, such as the circumstances of individuals involved, the elders feelings about their financial situation, and the elder's financial status. For example, one Younger Adult stated, "That's what's so frustrating about this. It is so what if, what if. What if that's just it. That's the grey area."

They also discussed the role of expectations and norms about appropriate financial transactions within families as a potential factor in abuse. All groups acknowledged that some children express an inappropriate degree of entitlement toward their elder relative's money/assets, with the expectation of future inheritance of the money/assets in the elder's will underlying their sense of entitlement:

> (Aged Care Worker): They feel entitled. They say it's gonna be my money anyway.
> (Older Adult): I think a lot of children think they should get from their parents. Entitlement. And before they are dead.
> (Younger Adult): There have always been hand-downs from inheritance, money going through the family, so maybe they already feel like they are entitled to it?

Also common across the groups was the belief that abuse typically stemmed from personal greed or selfish individuals:

> (Aged Care Worker): Greed and personal gain.
> (Older Adult): Greed. Pure and simple.
> (Younger Adult): It's easier for immoral selfish people to take advantage of their [parent's] generosity.

All groups expressed the view that elder abuse would include behaviors such as using an elder's assets but not for the elder's benefit, preserving an elder's assets for one's own benefit, denying an elder access to their assets, or providing an elder deceptive, incomplete, or misleading information upon which they are subsequently required to make a financial decision. In addition, members of all groups reported abuse could include behaviors involving manipulation, coercion, and emotional pressure to separate an elder from their money/assets:

> (Aged Care Worker): There is that sort of psychological abuse behind the financial abuse. There is a deliberate, can be a deliberate manipulation by a family member.
> (Older Adult): The emotional blackmail that goes into removing their assets. . . . That's right there is pressure to do things that you normally wouldn't.
> (Younger Adult): She used her mother's house as security for a property she was buying without her mother's knowledge, then when the mother wanted to sell her own place she talked her out of it.

There was widespread support for increasing formal regulations to protect older people, like appointments of EPAs (financial), the need for individuals appointing EPAs to have their decision-making capacity properly assessed, and increased regulation of how finances are spent once an EPA is activated. Overall, groups discussed reducing financial abuse through EPAs fatalistically, referring to the need to simply trust others and hope that they will act in the elder's best interest:

> (Aged Care Worker): Also people give EPA to people they believe they can trust. It's just something they do, trust their family. . . .
> (Older Adult): I think you have to trust whoever you give it to and just hope that they. . . .
> (Younger Adult): She is a good lady and very trustworthy but if she was not, she would have everything.

Different Group Attitudes

Attitudes regarding a specific issue emerged strongly in one or two focus groups but not all three groups. Alternatively, the groups could express different attitudes regarding the same issue. Some of the issues on which the groups' attitudes seemed to differ are presented in Table 5.

The capacity of older people to manage their financial affairs was discussed by each group. In comparison to the other groups, Aged Care Workers expressed the strongest attitude that older people were more likely to have difficulty managing their affairs independently. They were also

TABLE 5 Differences Across Groups (Aged Care Workers, Older Adults, and Younger Adults)

- Capacity of older people to manage their finances/assets independently
- Who the most likely abusers are (e.g., institutions versus family)
- Types of prevention strategies recommended (e.g., formal measures versus education)
- Reasons for vulnerability of older people (e.g., disability versus lack of education)
- Some behaviors considered abusive (e.g., providing misleading information)
- Reasons why financial abuse occurs (e.g., greed versus generosity of victims)
- Expectations and norms about appropriate financial transactions within families (e.g., borrowing/lending money)
- Role of social values, morals, and culture

more adamant that financial abuse could be reduced by increasing formal regulations for financial transactions occurring within families (e.g., loans, contracts). They suggested that older people should routinely consult financial or legal professionals when they made big or significant financial decisions. For example, one Aged Care Worker said, "Often within [these] families money exchanges hands, and they borrow many thousands, without anything written." Another added, "If that family could go to the bank, and get a loan, then that's what they should do. Just like all of us do, instead of cutting corners." Interestingly, they expressed ambiguity with regard to whether they would want greater formal regulations imposed on themselves, suggesting that what they were recommending may be idealistic and not necessarily desirable or practical. For example, one Aged Care Worker said, "This is all very good because we are looking after these old people but we are the next generation. Don't forget we are going to be in the exact same situation, so what we are suggesting can impact on us." In contrast, Older Adults generally considered themselves intellectually "capable" of managing their financial affairs, but suggested many put themselves at risk of abuse by failing to obtain information on how to manage their affairs properly. They also agreed that older people need to take a degree of responsibility for falling for scams by failing to find out enough information, failing to read the fine print, or being greedy themselves. For example, one Older Adult said, "Just greed, that's the other side of taking up these things." Through their discussion, however, many became surprised at their own lack of understanding or knowledge around certain issues. They also expressed inner conflict between wanting to trust others and at the same time remaining vigilant and sceptical. For example, one Older Adult said, "Some of these stories about children astound me a bit." Another said, "What do you do, you get a solicitor to check the solicitor to check the first solicitor?" In contrast to the other groups, Younger Adults expressed the broader view that an older person's capacity to manage their financial affairs would significantly depend on the cognitive ability of the individual.

The groups differed in their perception of who were the most likely perpetrators of financial elder abuse. The Aged Care Workers identified family as the primary perpetrators of abuse and did not discuss institutional abuse

at all. In contrast, the Older Adults considered institutions as the primary perpetrators of financial abuse and discussed examples of institutional abuse at length. Although Older Adults identified relatives as also being potential abusers, they expressed the view that protecting oneself from family members was almost too difficult and that older people essentially needed to trust that their family would behave appropriately. Several Older Adults stated they were not concerned about the risk of abuse from their family. For example, one said, "As with MF, it's the institutional ones that get up my nose." Another said, "Well, that's a matter of trust . . . our eldest son has complete power over us, my wife and myself. I'm not in the least concerned about that." Younger Adults discussed both family members and professionals as being potential abusers of financial elder abuse, but identified family as the most likely because professionals had clearer ethical and professional boundaries to abide by than families. For example, one Younger Adult said, "If it is a professional then there is that line that you can't cross and there is no grey area."

When identifying risk factors for financial abuse, all three groups identified and discussed the vulnerability of older people. However, the groups differed in terms of how they thought vulnerability put older people at risk and how important vulnerability was relative to other risk factors. By way of illustration, the Aged Care Workers discussed the vulnerability of older people being primarily due to medical problems, dementia, and feelings of powerlessness against the abuser. For instance, one Aged Care Worker said, "Older people are a bit more vulnerable regardless . . . they've got that sense of powerlessness you know, especially if they've got medical problems. . . ." Older Adults considered a lack of education or experience with money management, particularly for women, as an important reason for their vulnerability. For example, one Older Adult said, "I think women or people older than us haven't had as much experience as we have had. They were the women whose husbands did everything . . . I think they are easily lead because they've always been protected." In contrast, Younger Adults expressed the view that older people could be more vulnerable due to their generous nature (e.g., "Usually old people [have] got this really giving and generous nature"), as well as fear of losing social supports and friendships (e.g., "Someone might feel pressured to help their grandchildren or children, because they feel like they would turn their backs on them if they don't do that"). They also mentioned factors like dementia, lack of education about financial elder abuse, and lack of experience with money management.

When discussing other potential causes of financial elder abuse, Aged Care Workers talked at length about family dynamics and complexities, such as competition among siblings to gain assets, elders attempt to preserve assets for their children, and a lack of separation of finances within families. Addictions such as gambling also were mentioned as factors that could impact on family dynamics. For example, one Aged Care Worker said, "I

think sibling rivalry might be a bit of a factor because if one sibling starts trying to get personal gain, the others will try to protect their own interest," while another said "The money is all enmeshed, and you know that person's sold their home and now living with the extended family." Older Adults also mentioned competition among siblings and elders preserving assets for their children. However, they expressed the view that children frequently believe older people do not need money and therefore should help them financially. For example, one Older Adult mimicked a young person saying, "You've got it, you are not using it, so I should have it!" Unlike the other groups, Younger Adults expanded their discussion on the role of family to include the role of cultural norms, morals, and social values. They agreed that different expectations within cultures made defining and preventing financial abuse difficult. For instance, one Younger Adult said, "But that all depends on the culture as well. What some cultures find acceptable; some cultures don't." Furthermore, Younger Adults considered the loss of social and moral values, such as respect for elders within the community, as a major reason for financial elder abuse (e.g., "We've lost that sort of social respect and family values from our lives").

Borrowing money from elders was viewed differently by the three groups. Aged Care Workers considered borrowing money from an elder as financially abusive when the money or assets were no longer available to the elder or not returned as soon as the money or asset was needed. Younger Adults did not consider borrowing money from elders as financially abusive behavior as long as the money was eventually returned. Older Adults agreed that when they lent money to their children, they rarely expected the money to be repaid with interest, or at all. For example, one Older Adult said, "But when it's your children . . . you have to expect that you won't get it back and if you do it's a bonus."

In terms of interventions, Aged Care Workers considered professional involvement in the elder's financial affairs (e.g., creation of legal documents and contracts) as a good preventative strategy and expressed favorable attitudes toward the appointment of formal Administrators by the Victorian Civil and Administrative Tribunal (VCAT). In comparison, Older Adults considered education as the best preventive strategy, in order to improve older peoples' ability to make good financial decisions and detect scams. They also agreed that younger people need more education from their parents about money management so they would not require financial assistance from their parents. For example, one Older Adult said, "I just want an education program of some sort to help people that could do with the help." Another Older Adult said, "I think it comes down to educating your own children." Younger Adults also discussed education as an intervention, but in terms of educating young people to respect their elders rather than their need for financial management skills. For instance, one Young Adult said, "We kind

of need to rebuild that social respect that we have clearly lost." Furthermore, Younger Adults discussed increasing the elder's social support network as a good strategy for reducing financial elder abuse (e.g., "They were very sheltered, there was no media, full stop. We have all this knowledge at a very young age").

Specific Individual Attitudes Expressed in Focus Groups

Although each focus group involved participants expressing a view on an issue raised, at times an individual expressed a view that stood out as being very different to other views raised in that group and/or the views raised by members of other groups. These views are worth documenting, as it is possible that these views are legitimate but less socially acceptable or brought to the group from an individual's experience or unique perspective on the situation. For example, one Aged Care Worker (LP) expressed a strong view that family members should not be reimbursed for providing care to their parents:

> I think people rationalize it by saying that, "Well, look I'm doing this for you, so you should pay me to do it" . . . where really it's a relative and you shouldn't have to be paid for doing it . . . it's a part of your role, your duty almost.

However, another group member (AD) firmly believed financial reimbursement was acceptable if the elder would have to pay for the service externally, and paying family members for services could be important for maintaining a sense of independence and autonomy:

> If you take on the role of a Power of Attorney there are a lot of costs incurred with carrying out that role, that if it went to an Administrator or the State Trustees they actually get paid for doing that. . . .

When discussing potential reasons for the occurrence of financial abuse during the Older Adults focus group, one participant suggested that it is within human nature for people to target those they perceive as weak to further their own interests:

> But the strong have always preyed on the weak. It's a historical thing that if you've got it, and someone hasn't, and they've got the ability to get it off you then they will give it a go.

Although the majority of Younger Adults agreed that borrowing money from an elder is acceptable as long as the money is returned, one participant

raised the view that borrowing money from an elder is financially abusive because it indicates a lack of respect for the older generation:

> It might even be abuse asking to borrow in certain circumstances, because it's almost abusing that trust . . . the respect that we should have for the elder generation.

In contrast, another Young Adult expressed the strong view that older people should provide for their children financially for several reasons, including older people not needing the money, to ensure the happiness of their children, and to show the value of personal relationships:

> You have them (children) because you want to shower them, you want to give them the money, you want them to be happy in life. Why would you think of them as a distant third person saying, "No I'm not giving you money, I'm going to make you earn it yourself." I do not understand that concept . . . They want you to come to them and ask them for something so that you are showing, "I acknowledge that you are my grandma and I can come to you for anything . . . Think about what you value. Do you value money over relationships?"

DISCUSSION

The aim of this study was to investigate community and individual attitudes toward financial abuse of the elderly in Australia, using three focus groups that included different segments of the community: Aged Care Workers, Older Adults, and Younger Adults. The focus groups revealed a range of views about what participants thought financially abusive behavior was, why it occurs, and how it can be prevented. On some issues, all three groups expressed similar views, on other issues the groups expressed slightly different views, and on particular issues individuals expressed strong but unique views from those expressed by other participants in the current study. It is possible that views or attitudes expressed by participants across all groups are those more commonly held in the community. They also may represent the most socially acceptable views that are universally endorsed in group discussions, but not necessarily held by all individuals. The views expressed by participants in one or two groups, but not by all three groups, may represent attitudes more specific to a subgroup (or subgroups) of the community, such as those with experience working in aged care. Finally, more unique views expressed by particular individuals (and not necessarily agreed with by others) may represent less socially acceptable views and/or be reflective of an individual's unique personal experience or perspective on an issue.

The present study revealed that participants across the various groups agreed that financial elder abuse was a complex social phenomenon that was difficult to define due to different familial norms and expectations with regard to inheritance, loans, financial transactions, and the provision of unpaid services and support within families. However, certain behaviors were endorsed as being potentially abusive by all groups, such as using an elder's assets for purposes other than the elders benefit or deliberately preserving the elder's assets for one's future inheritance, resulting in the elder receiving suboptimal care. All groups mentioned deliberate manipulation, coercion, or emotional pressure to gain assets from an elder as a common factor in abusive situations.

Consistent with previous research, members of all groups described greed and a sense of entitlement to the elder's assets (due to an expectation of inheritance) as motivating factors for abuse (Dessin, 2000; Jayawardena & Liao, 2006; McCawley et al., 2006; Tilse, Setterlund, et al., 2005; Tilse et al., 2007). Also consistent with previous research, all groups described older people as being more vulnerable to financial abuse than other members of the community, despite expressing different views as to why they are more vulnerable (Bond, Cuddy, Dixon, Duncan, & Smith, 1999; Choi & Mayer, 2000; Dessin, 2000; Hafemeister, 2003; Malks et al., 2003; Tueth, 2000; Wilber & Reynolds, 1996). Finally, all groups thought closer monitoring of financial EPA appointments and their activities would help protect elders from abuse.

Despite the many similar views held by participants in this study, there were marked differences among the three groups in some of the attitudes expressed and the way the topic was approached generally. These differences are important to consider as they highlight potential variability of "social norms" and may influence the behavior by individuals who identify strongly with these groups or segments of the community. For example, Aged Care Workers, perhaps due to the nature of their work, considered older people vulnerable due to mental and physical disabilities resulting in greater dependency on others for support. They considered older people generally less able to manage their own finances competently, and that relatives were the most likely perpetrators of abuse, consistent with empirical research (Boldy et al., 2005; Choi et al., 1999). Accordingly, their ideas for prevention of abuse included greater professional and formal regulations, particularly for within-family financial transactions. In contrast, Older Adults expressed the attitude that many older people were capable of making sound financial judgments but failed to do so because of lack of experience, education, and even the victims own greed (i.e., trying to obtain something that was "too good to be true"). They considered institutions and strangers (including professionals like financial advisors) as the most common perpetrators of abuse, which included Internet scams. Accordingly, they believed the best prevention would be to educate both older and younger people to better manage their own finances and to detect scams, including those

where important details were concealed within the fine-print of "terms and conditions," as previously suggested in the literature (Boldy et al., 2005; Choi & Mayer, 2000; Rabiner, Brown et al., 2004; Tilse, Wilson, et al., 2005). Finally, Younger Adults approached the discussion topic in broad philosophical terms (e.g., the loss of values, morals, and respect for the elderly in society, the role of culture), possibly due to a lack of personal experience with elder abuse. They generated a broad range of responses for each of the discussion prompts, and this likely contributed to their overall view that the issue was very complex and context dependent (e.g., whether the perpetrator was family or not; whether victim was cognitively impaired or not; whether the behavior was consistent with family and/or cultural norms). Their ideas for prevention included strategies primarily targeting older people, such as better social support, legal options, and financial education. Unlike the Older Adults, they did not consider better financial education of younger adults as a potential strategy for prevention of financial elder abuse.

Unique views expressed by individuals in the current study included the notion that family are dutifully obliged to support other family members without the expectation of financial reimbursement, that it is appropriate for family to be paid for providing services that would need to be paid for if performed by strangers, that many older people may find paying family for services as a way of maintaining/asserting their independence and autonomy, that asking older relatives for money demonstrates a lack of respect for the elder, that elders want younger family members to ask them for assistance, and that denying financial assistance to family members suggests that money is being valued over familial relationships.

Many of the attitudes expressed by participants in the current study are consistent with those found in previous research, such as the study by D'Aurizio (2007) on community attitudes to elder abuse. However, a number of attitudes reported here have not been reported previously in the literature, such as the notion that some elderly people fall victim to abuse due to their own greed when trying to obtain something too good to be true, or that taking money from an elder relative for services may be important for the preservation of the elder's sense of independence. This may be due to the qualitative data collection method used in this study, which allowed a more in depth exploration of the topic than, for example, structured survey methodology. It is difficult to determine whether some of these previously unreported attitudes are actually common in the community without conducting a larger and broader survey of the community. However, the information collected in this study could be used to inform the development of a new survey better able to assess the diversity of attitudes held in the community.

There are obviously a number of methodological issues that could impact on the interpretation of results of this study; however, we attempted to identify these issues prior to collection and interpretation of the data to minimize their impact as much as possible. Firstly, due to the small number of participants in each focus group, it is obvious that attitudes expressed

by the members of each of group cannot be interpreted as a true representation of the views held by all members of these "demographics" in the community (e.g., younger people, older people). In addition, some of the views expressed and concurred by members of one focus group but not others may not reflect a real difference in attitudes between the groups, as members of the other groups may have concurred with the same view had it been raised within their focus group. Secondly, the views expressed by individuals during the focus groups may or may not be reflective of their personal attitude or belief, but may be a socially acceptable or desirable view that could potentially deviate quite significantly from their personally held attitude. Although socially desirable responding is a potential limitation, the discussion prompts or questions did not explicitly ask participants to state their own personal attitudes, so it is possible that participants responses were a mixture of their own attitudes, attitudes of others they have heard or read, and socially desirable attitudes. It is possible that a confidential survey may be a better way of investigating individual's personal or private attitudes on this topic. Another potential limitation of the study would have occurred if the focus group moderator was influencing the groups' discussions. Attempts were made to minimize this problem by generating neutral probe questions prior to the focus groups (e.g., Can you tell me more?, What do others think?), therefore reducing the potential for the moderator to impose their personal expectations and attitudes into the discussion. Finally, qualitative data analysis and interpretation has the potential to introduce subjective bias into the results (Madill, Jordan, & Shirley, 2000). Attempts were made to enhance the reliability and validity of the study by involving two researchers at each step of data coding, transcribing, thematic extraction, and interpretation.

Conceptual models of elder abuse (Schiamberg & Gans, 2000), or financial elder abuse more specifically (Rabiner, O'Keeffe et al., 2004), highlight the importance of considering both individuals' attitudes as well as social and cultural norms as factors involved in the existence of financial elder abuse in the community, as suggested by theories of attitude-behavior relationships (Ajzen, 1991; Smith & Louis, 2009). The results of this study support the existence of both these factors and extend on these models and previous literature by providing empirical support that people within the community have both shared, different and individual attitudes about financial elder abuse that require further exploration due to their potential to cause or avert abusive behavior in society and the likelihood that individuals will intervene in suspected financial abuse cases.

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Managing older people's money: assisted and substitute decision making in residential aged-care

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ABSTRACT
Current approaches to the assessment of cognitive capacity in many jurisdictions seek to balance older people's empowerment with their protection. These approaches incorporate a presumption of capacity, a decision-specific rather than global assessment of that capacity, and an obligation to provide the support needed for adults to make or communicate their own decisions. The implication is that older people are assisted to make decisions where possible, rather than using substitute decision makers. For older people, decision making about financial matters is a contentious domain because of competing interests in their assets and concerns about risk, misuse and abuse. In residential-care settings, older people risk being characterised as dependent and vulnerable, especially in relation to decisions about financial assets. This paper reports an Australian study of the factors that facilitate and constrain residents' involvement in financial decision making in residential settings. Case studies of four aged-care facilities explored how staff interpreted the legislative and policy requirements for assisted and substitute decision making, and the factors that facilitated and constrained residents' inclusion in decisions about their finances. The observed practices reveal considerable variation in the ways that current legislation is understood and implemented, that there are limited resources for this area of practice, and that policies and practices prioritise managing risk and protecting assets rather than promoting assisted decision making.

KEY WORDS – capacity, substitute decision making, financial management, residential care.

Background

Policy and practice interest in older people's decision-making capacity for financial matters has arisen from broad concerns around preserving and

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protecting assets for later life. Financial resources are central to older people exercising choice in living and care arrangements. Access to and control over decision making about money and property in older age also have psychological, cultural and social meaning, provide security, and symbolise continuing independence. Decision making about how assets are preserved or spent generates complex issues for older people, family members, formal carers, professionals and service providers (Langan and Means 1996; Tilse *et al.* 2007*a*). The complexities around the assessment of capacity for decision making in relation to financial matters and concerns about prevention and intervention in relation to financial abuse of older people have stimulated research and policy and practice interest (Letts 2009; McCawley *et al.* 2006).

Making decisions about assets requires a broad range of cognitive and procedural skills (Moye and Marson 2007). Diverse tasks, such as basic cash transactions when shopping, banking, paying bills and securing personal valuables, differ from long-term decision making about the conservation of financial resources. Impairment in cognitive capacity, communication difficulties and/or health, mental health or mobility problems can all affect an older person's capacity and willingness both to participate in some of the decisions and to implement decisions once made. The natures of the impairment and of the available support interact and affect an older person's capacity to engage with particular financial tasks.

Legislative changes in several countries have reflected changes in thinking about capacity assessment and the context in which decisions are made. A recent legal development is the shift from a global determination of capacity, based on the presence of a diagnosis alone, to a consideration of key functional abilities relevant for specific domains, including decision making about financial matters, entry into residential care, and consent for health-care treatment (Dwyer 2005; Grisso 2003). Legislative changes in Australia (Queensland Government 2000: *Guardianship and Administration Act 2000*, Chapter 2, Section 5), England and Wales (United Kingdom (UK) Department of Constitutional Affairs 2007: *Mental Capacity Act 2005*, Section 2, Principles 1 and 2), Scotland (Mackay 2009), Canada (Ontario Ministry of the Attorney General 2005), and the United States of America (Moye 2003) reflect this shift in principle. The new policy approaches incorporate a decision-specific approach which recognises that capacity to make decisions differs according to the nature and extent of the impairment, the type of decision to be made and the available support. The legislation seeks to achieve a balance between protection and empowerment based on a presumption of capacity and an obligation to provide the support needed to help adults make or communicate their own decisions (Johns 2007). The legislative intent appears to be that capacity to make a particular decision

in a particular context is assessed in relation to each matter. Where possible, the older person is assisted (or supported) in making their decision rather than having that decision referred to a substitute decision maker.

Some research has challenged whether this changed approach to decision-making capacity is appropriately understood and enacted in professional practice with older people. In an American study of health-care professionals, Ganzini *et al.* (2003: 241) noted that one pitfall in assessing decision-making capacity was little understanding that capacity or incapacity is not 'all or nothing' but rather specific to the particular decision. These authors made the point that if a clinician conceptualises a patient as globally lacking capacity, it is likely the patient will not be given the opportunity to make various decisions that he or she in fact has the capacity to make. In the Australian context, Bennett and Hallen (2006) called for greater understanding by medical practitioners of guardianship and financial management legislation. Wilson *et al.* (2009) argued that social workers need to open up opportunities for older people to be involved in making decisions about their financial assets. In the UK, the *Mental Capacity Act 2005 Code of Practice* (UK Department of Constitutional Affairs 2007: Chapter 3, 3.5) proposes that providing 'appropriate help with decision-making forms [is] part of care planning processes for people receiving health or social care services'. This includes providing relevant information, communicating in an appropriate way, making the person feel at ease and exploring who might support the person to make choices or express a view. The extent to which everyday practices in community and residential aged-care reflect these legislative principles is currently poorly understood across a range of disciplines.

Practice that is in keeping with these legislative and policy principles requires not only an assessment of capacity to make a particular decision but also an understanding of the nature of substitute and assisted (or supported) decision making together with a willingness and ability to retain the older person's involvement. Substitute decision making in relation to financial matters may be a formal or informal process (Tilse *et al.* 2005). In all cases there is a moral and, under some legislation such as the UK *Mental Capacity Act*, a legal imperative for decision makers to act in the best interest of the older person and, as far as possible, to take their wishes into account. Formal substitute decision-making instruments (commonly called enduring, durable or lasting power of attorney, financial guardianship, or administration orders) address impairments in decision-making capacity by providing legal authority for others to make financial (and other) decisions for older people. Jurisdictions vary, first in the type of decisions covered by the power (*e.g.* financial property, health and/or personal

care), second in their ability to specify what decisions are and are not to be made, and third in determining whether the power comes into effect immediately, at a specified time, or when incapacity to make the decision is established. What is common is that an enduring or lasting power of attorney is made when the donor (or principal) is capable of making his or her own decisions and is able to understand the consequences of preparing the document and its contents; and for the power to endure if the donor loses capacity. Criticisms of these instruments are based on concerns about whether their use achieves a balance between empowerment and protection (Wilbur 2001). Under the United Kingdom *Code of Practice for the Mental Capacity Act*, attorneys acting as a 'lasting power of attorney' have a legal duty to have regard to this *Code of Practice*, which describes their responsibilities when acting or making decisions on behalf of individuals who lack the capacity to act or make these decisions for themselves.

Many decisions about an older person's involvement in financial management are also made informally (Ganzini *et al.* 2003), by family carers (Tilse *et al.* 2005), and by managers and staff in community and residential care. Family members and formal carers may not understand or act in response to the duties that run alongside the power they have either been formally given, as by an enduring or lasting power of attorney, or have informally assumed. Research that explores the experiences of community care staff in relation to 'money handling' for clients has identified the need to improve training, support and good practice guidelines (Means and Langan 1996). Although the importance of assisted (or supported) as well as substitute decision making is a key implication of current policy, how this operates in various care settings is not well understood. Effective assisted decision making means determining and taking into account the wishes of older people and offering them the resources that make the difference between what they can do for themselves and what needs doing by others to reach or execute a decision (Wilson *et al.* 2009). Assisted and substitute decision making should take account of the context in which the asset management takes place and negotiate the fit between the tasks or decision to be made, the older person's wishes, the formal or informal carer's willingness and ability to respect the views of the older person, and the available support. Providing this form of support is not always easy, in part because professionals usually become involved in older people's lives at important decision points such as entry into residential care when the situation 'is not conducive to facilitating and respecting decision making by older people' (Dwyer 2005: 1089).

Older people are diverse and their interest in financial decision making varies. Research exploring the perspectives of older people receiving assistance with managing assets has highlighted the variation in older

people's wishes in relation to decision making (Tilse *et al.* 2007*b*). These range from a preference for either assisted decision making with help to implement and monitoring the decisions (including being consulted and having access to accounts), to ceding decisions to substitute or proxy decision makers on a basis of trust that their assets will be well managed. Research with informal carers in relation to asset management has identified a range of practices, attitudes and environments that include or exclude older people in decision making about their assets (Tilse *et al.* 2005*a*). Inclusive practices can be described in terms of the level of the involvement of the older person in decision making and the degree of fit with their preferences (Tilse *et al.* 2005, 2007*b*). A strong issue for carers is the dilemma of balancing the independence and self-determination of the older person with the need to protect their assets, and reconciling this aim with the carer's need to have effective and time-saving practices in place. In response to these pressures, some carers continued with assisted decision-making approaches, and others found acting as a substitute decision maker more convenient. How care staff in residential settings manage these tensions is little understood.

Residential-care facilities are important environments for understanding care practice in relation to current legislation. Older people in residential care are likely to be defined in terms of 'complex needs' and 'dependency' at the expense of being seen as adults capable of making a range of decisions (Scourfield 2007: 1136). The tasks and responsibilities of residential-care staff in relation to managing money and property differ from those of informal carers. The Australian Government Department of Health and Ageing *Aged Care Act 1997* and *User Rights Principles 1997* recognise, through a *Charter of Residents' Rights and Responsibilities*, the resident's right 'to maintain control over, and to continue making decisions about, the personal aspects of his or her daily life, financial affairs and possessions' and 'to have access to services and activities which are available generally in the community' (Australian Government Department of Health and Ageing 1997: Section 10.13). Unlike family, residential-care staff members do not have a decision-making role in managing residents' finances. Their responsibilities are first, to support residents who are able and wish to self-manage their assets or participate in tasks such as banking, shopping and consulting with financial advisers, and second, to help residents keep their money and valuables safe.

Assisting older people to remain involved in decision making about money and property poses particular challenges in residential aged-care environments. These include: the high level of impairment of many of the residents and the high prevalence of dementia (Australian Institute of Health and Welfare 2007; Knapp and Prince 2007); that the communal

setting means that cash, valuables and documents are at particular risk of loss, misuse and abuse; and the constraints on the roles of formal care providers in the financial affairs of residents. Little is known about how residential-care staff members manage these tensions or about the extent to which the spirit of the current legislation is reflected in day-to-day practices. The paper draws on findings from an in-depth study in Australian aged-care facilities of the residents' participation in decision making about their assets. It specifically explores assisted and substitute decision making in this context.

Research overview

The Assets and Ageing Research programme at the University of Queensland comprises eight interlinked projects on the management of older people's assets in Australia (Tilse *et al.* 2007*a*). The programme defines asset management as having some control over access to, organising, making decisions about or using an older person's financial or capital assets or valuables. Older people are defined as those aged 65 and over, but in the majority of studies most participants have been aged 80 or more years. All studies have taken place across urban and rural locations in South East Queensland, Australia. The data reported in this paper were collected through case studies of four residential facilities. This in-depth study explored policies and practices relating to residents' participation in accessing, managing and decision making about their finances and property. All facilities had a mix of residents requiring high and low levels of care, and all were subject to Australian government regulations and the *Charter of Residents' Rights and Responsibilities*. The sample of aged-care facilities (ACFs) in South East Queensland was selected to ensure inclusion of urban and rural locations, large (more than 150 residents) facilities that were part of a chain and small (less than 60 residents) facilities that were not and so had fewer levels of management. One facility specifically provided for people from culturally and linguistically diverse backgrounds.

The data were collected using semi-structured interviews with 102 participants. These consisted of 10 care managers and business managers, 48 care staff including registered nurses, personal care assistants and support staff, 12 residents and 32 residents' family members. In addition, there was an analysis of written policies and handbooks relating to residents' assets. This paper utilises data from interviews with care and business managers and direct care staff. Understanding the policies and practices from the perspective of staff is a vital first step in charting how changes in legislative principles and codes of practice are understood and implemented. While

the case studies of four facilities do not allow generalisations, they provide an in-depth exploration of this complex arena of care provision in specific contexts. The case study analysis provided the basis of a survey of a representative sample of aged-care facilities in the next stage of the project. The thematic analysis of the interviews sought to answer the following questions:

1. How do ACF staff interpret the legislative and policy requirements for assisted and substitute decision making?
2. What factors facilitate and constrain ACF residents' inclusion in decision making about their finances and property?

Findings

The case studies showed that although asset management was most commonly undertaken on behalf of residents by family members or public and private trust organisations, all facilities reported having a small number of residents who self-managed all or some of their banking, shopping, bill paying and investment transactions. Most of them were described as having no cognitive impairment or having family support to remain actively involved in managing their financial affairs. Across the four facilities, a range of opportunities for and constraints on assisting residents to remain involved in some of the tasks of managing assets were identified. These arose from how the legislative requirements that relate to substitute decision making were understood and used, in particular 'enduring powers of attorneys' (EPA); how the responsibility to assist residents to continue to make some decisions was viewed and resourced; and the concern to minimise risk of loss or and allegations of misuse of assets.

Interpreting legislative requirements

Various interpretations of existing legislation were evident in the interview data. In Queensland, a donor of an EPA can specify a time when it comes into effect. If no time is specified, then the attorney is able to exercise their financial decision-making power immediately but is nonetheless required to consult with the donor if the donor has capacity for the decision (Queensland Government, Department of Justice and Attorney General 2010). All facilities requested copies of EPAs upon the admission of the older person, but how these were understood and then used in respect of financial matters varied. Apart from the time of admission, only one facility had a system in place for checking the conditions of the EPA when

an attorney sought to use it. In one facility, the business manager reported that the holder of the EPA (the attorney) was the preferred point of contact and viewed as the primary decision maker regardless of whether or not the resident had capacity to make that decision. An example of this was consulting the attorney about a resident's decision to buy clothes when the resident clearly had the capacity to make that decision. A business manager commented:

> We become accustomed to dealing with the [person who has] the power of attorney. Our first instinct is to [contact] the power of attorney but they usually ... say, 'oh well, mum and dad still look after their own affairs'.[1]

This approach does not reflect a decision-specific assessment of capacity or an understanding of substitute decision making. Some staff also reported that some family members assumed a substitute decision-making role when the resident was willing and able to retain involvement. As one explained:

> [the resident] has been placed into care, has established his enduring power of attorney and the family seem to have taken over. They are making the major decisions for him and he's angry. He's a very angry person because he feels that everything has been taken away from him, like the whole dignity of his life has been taken away.

An alternative view from a manager in another facility reflected a clearer understanding of the principles underpinning substitute decision making: 'if the person [the resident] has cognitive capacity we would take whatever their wish is over the EPA [the attorney]'. The manager, reflecting on the practices in some facilities of referring to the holder of the EPA for all decisions commented, 'I can see why that happens but it is not right all the same. Because it is a cop out. It is easy to do that'.

Responsibility and resource constraints

A second barrier to assisting residents who were able and wished to have some involvement in managing their financial affairs arose from how the facility role was viewed and resourced. Some facilities took the view that assisting residents to retain an interest in managing some tasks of asset management was not part of their role and very much in the domain of families. These facility managers were much more likely to refer automatically to substitute decision makers for any decisions involving money. As one manager noted, 'we have care responsibilities, not financial responsibilities'. From this perspective, all financial matters and tasks – not only managing fees and charges and the more complex tasks of asset management – were seen to be the concern of families or trust organisations rather than of the resident or the facility's staff.

An alternative approach that acknowledged that the facility had responsibilities in this domain was also evident. In these facilities, managers and most personal care staff reported that it was important to support independence in asset management, especially in the situation where a resident had no family member to assist them. Diversional therapists or others who organised outings reported taking residents shopping or to the bank. One diversional therapist described her involvement:

> Well he is in a wheelchair, okay, so we go over and I just stand beside him at the ATM [automatic teller machine] in case he has a problem. ... If he has a problem, he will ask me and I will help him sort it out like maybe he hasn't pressed the numbers properly. ... Then we go into the stores. I push him. He says what he wants ... then we will go to the checkout. He has the money in his wallet. He takes it out and pays ... and gets the receipt and the change and puts it back in his wallet. So he has control of that. I don't touch it at all.

Care managers who supported this approach reported that it was resource intensive and could be difficult to facilitate. For example, assisting a resident to visit a bank required a staff member to escort the resident to the bank, arrange transport, and organise back-up staff to replace the absent staff member. As one care manager reported, 'It's all very well for us to say that the resident should have total independence but I've got to release a staff member for an hour at least. They have got to have transport and who pays for that?' In one case where an escort could not be arranged through the diversional therapy programme, the resident herself provided the funding for staff costs and transport to enable her to manage her own banking. Not all residents could afford this. In another facility, residents could access a bank only if they were able to do so without facility support. The rural facility reported a range of practices that included a front-line staff member taking a resident to a local bank. The manager said:

> It's not our role. ... I've taken her down to the bank to sort out getting monthly bank statements now that ... her one eye is done [has been operated on] so that she can see. ... We were going to do phone banking with her but we decided that she could get monthly statements and she was happy with that. So I just walked down to the bank with her one afternoon. But most of the time, we hand it over to families or a person holding the EPA.

Managing 'risk'

Managing risk also presented a barrier to supporting residents to remain involved in decision making about money and property. Risk in relation to a resident's involvement in banking and other asset management tasks was primarily handled by referring financial decisions to family members or appointed attorneys rather than supporting the resident to remain

involved. The day-to-day management of money and valuables in the facility was, however, a core concern of the care managers, all of whom sought to minimise the risk of money and valuables being mishandled, lost or stolen and to reduce allegations against staff of theft or undue financial influence. All senior staff saw the management of such allegations as extremely difficult and time consuming. They reported that the best option they have found is to ask residents to keep no or very small amounts of cash in their rooms. All the facilities actively discouraged bringing valuables, especially jewellery and money into the home, and all had transparent and well-developed practices around handling residents' money and to protect the residents' cash and valuables. Policies and practices that promoted resident involvement in decision making, however, were much more limited because the facilities managed risk by reducing residents' access to money and valuables. A business manager summed up his approach:

> The families are always advised when their family member comes in to keep their personal property down to a very minimum. ... I think it should be a regulation that they leave those sorts of personal belongings at home. Even though it should be their right to bring them in.

Cash was most commonly held at the office rather than in residents' rooms, and/or any incidental expenses for outings or shopping were often debited to the resident's account so that cash was not directly handled. For example, one care manager indicated that money is debited to the account 'when the resident has their hair done etc., newspaper and any other ongoing things so that makes life a lot easier for the resident'. A personal care worker explained the procedures associated with outings:

> We get a blank cheque from [the general manager]. We order the meals and we order drinks and it is just one cheque and the receipt comes back to the office. The names are recorded of the people who went on that bus trip and they work out ... how much is owed [and then it is taken from the accounts].

Removing access to cash and valuables is an appropriate practice for protecting older people's assets and property and reducing the likelihood of allegations against the staff, but it pays scant attention to the residents' independence. Some staff, however, recognised the importance of access to cash for some residents. As one carer said:

> But if they get very worried about that then I usually get the office to ... give them a bit of cash so they do have some money and it stops playing on their mind that they have got nothing ... it could just be $5 or $20 ... as long as they have some money there in their pocket, that seems to be important.

This was particularly apparent in one facility that accommodated people from culturally and linguistically diverse backgrounds where it was understood that having cash was especially important for post-World War II refugees who had arrived in Australia with few possessions. Over all the facilities, however, practice indicated that the priority was to manage risks by protecting assets and protecting staff from allegations of misconduct. One care manager recognised some of the moral and ethical dilemmas of encouraging capable residents to remain involved with their assets:

> We are aware that in a lot of cases you are taking away people's independence and their ability to manage. It is done from, hopefully, you know, taking the high moral ground that this is the best thing for that [managing concerns about loss and allegations of theft].

A manager in an extra-services facility that charged higher fees and provided for residents with significant assets also noted the challenges to independence in current policies and the variation is resident responses:

> I mean they lose their homes, they lose their life and they also to a degree lose their money. Some of them are quite happy to. Some are quite happy to come and act like it is a bank and some – I think – there should be more of an avenue where they can have some sort of banking structure [independent access to a bank] so that they can maintain that financial independence, especially for the boys. It is very important for the men.

Discussion

Across the four case studies, there were two consistent findings about older people's involvement in financial decision making in residential aged-care settings. Firstly, that constraints were placed upon their ability to be involved in decision making, both at the level of managing assets and in the day-to-day handling of money and valuables. Secondly, that only limited support was provided for the residents who were capable and wanted to be involved. The frequent outcome was the use of substitute decision makers as the easier option. These findings indicated the impediments to implementing a task-specific approach to the assessment of the capacity to make financial decisions. The analysis of the case studies suggested that the opportunities and constraints in residential settings for implementing the current legislative principles that promote assisted decision making are defined by three intersecting factors: staff attitudes towards older people's rights to manage their assets, staff levels of knowledge of how to support substitute decision making, and the level of resources required to implement supported decision making.

The primary drivers of current policies and practices in the four ACFs were risk minimisation and resource constraints, together with a view that managing residents' financial assets is primarily the concern of family members. Staff involvement in supporting residents with their financial

assets was generally viewed as a risky and resource-intensive area of care practice. For some, it was simply was not regarded as part of their role. As a result, protection of staff time and reputation and the older person's assets were prioritised over empowerment and inclusion of the older person in decision making about their resources.

Substitute decision making mechanisms such as EPAs facilitate ease of asset management on behalf of older people and the identification of people with authority to act as proxy decision makers. This was an important resource for care providers, family members and for residents who were unwilling or unable to participate in decisions about financial matters, but the case studies show the limited understanding of the legislation and the principles underpinning the EPA instrument. While some staff had a sound understanding, inappropriate interpretations of EPAs were also noted. Some staff viewed the attorney as the primary decision maker regardless of any assessment of the nature of the asset management task or decision and the resident's capacity to make that decision or complete that task. In these situations, the older person's preferences were not explored. This misunderstanding and misuse of EPAs has been noted in earlier research on the practices of family members involved in managing older people's assets (Tilse *et al.* 2007*b*; Wilson *et al.* 2009). Resorting to using a substitute decision maker for all financial decisions provides informal and formal carers with a simple and convenient alternative to the more time-consuming practice of assisting older people to remain involved in decision making. In residential settings it can also reduce the risk of misuse and avoid potential conflict with residents' families at the expense of older people's rights.

The implementation of assisted decision making requires resources and support. The environmental and resource constraints revealed by this study showed the limitations of the support available and that this area of practice is under-developed. Although substitute decision making is well developed in legislation in Queensland, in many cases the strategies to achieve this and the resources associated with promoting assisted decision making and involving older people in asset management are inadequate (Tilse, Wilson and Setterlund 2009; Wilson *et al.* 2009). All facilities in the case studies provided safe areas for valuables. There was only limited evidence, however, of other environmental accommodations to assist older people to stay engaged in the tasks and decisions they were able to make (*e.g.* provision of accounts in large print, access to telephone and computers in aged-care facilities to assist the minority who seek to self-manage, transport to financial institutions and shopping). An understanding of day-to-day assessment of decision-making capacity in relation to a particular task also appears to be limited, with residents often viewed in a dichotomous way – as either being able to self-manage or as requiring family or trustee assistance.

Resource constraints affected opportunities to include older people in decision making. Taking time to assess capacity to make a decision in relation to a particular task, check that information is understood and communicate preferences creates extra tasks for residential-care staff. There was limited support for such tasks and few resources for innovative or experimental practices. Although the right to remain involved in financial affairs is recognised in the *Charter of Residents' Rights and Responsibilities* (Australian Government Department of Health and Ageing 1997), the regulators do not have specific guidelines on what this means in practice and do not assess this when accreditating facilities. In aged-care facilities where managing costs is a significant issue, providing the additional support needed for residents who wish to remain engaged with managing their financial matters is likely to be low priority and dependent on the particular interest and good will of staff members. In residential care facilities, the staff need the support of management to engage with time-consuming assisted decision making especially in relationship to financial matters where there can be risk of suspicion regarding the motives of care staff and possibly also family discord to be dealt with. Some staff in the smaller facilities provided examples of an individualised approach to assisting residents. Such tasks were often undertaken outside working hours in the staff member's own time.

Conclusions

Protection and risk management dominate current practice in aged-care residents' financial decision making, and limited attention is given to developing the skills and the resources required to assist older people to participate in the decisions they are able to make. Legislative principles are clearly not sufficient to ensure inclusive practice. Effecting change will require diverse strategies and commitment from a range of services and groups. To enact the spirit of substitute decision-making legislation in care contexts, all parties need to be aware of their rights and obligations, and all stakeholders need to be prepared and resourced to attend to older people's individual needs and capacities – in this case in relation to asset management – and to understand and respond to those needs and capacities as an integral part of their wider care. In communal environments such as residential care, providing individual attention, assessment and support in this domain of decision making can be easily overlooked and is poorly resourced.

In the UK, Chapter 3 of the *Mental Capacity Act 2005 Code of Practice* (UK Department of Constitutional Affairs 2007) provides practical guidance on how to support people to make decisions for themselves, or to maximise their role in decision making. This advice needs to be viewed in the wider context of resource allocation and service priorities. Johns (2007) and Manthorpe, Rapaport and Stanley (2008) noted the time and resource issues for professionals and informal carers resulting from their changing roles and responsibilities. Dwyer (2005: 1089) provided one example of time and resource constraints impacting on social workers' ability to work with the decision-making processes of some older people when decisions are to be made about permanent care. This example predates the introduction of the *Mental Capacity Act 2005* in the UK. It does suggest, however, that exploring how supported decision making is practised and resourced in line with the principles of this Act is an important area for further scrutiny by this profession.

Appropriate practice in line with current legislation involves an assessment of the context and the decision, an assessment of capacity to make the decision or the support needed to participate in decision making and the adult's wishes and beliefs and values (Letts 2009). For care providers, the need to be clear about when such practice is a moral and ethical responsibility and when identifying best interests is also a legal duty adds to the complexity of practice in this domain of care. These constraints on carers, paid or otherwise, need to be considered by government in the context of current regulatory requirements and funding arrangements in health and social care.

Practice in relation to assisted decision making involves skills in balancing power and risk, protection and independence in particular contexts. It also requires skills in assessing decisional capacity in relation to particular asset management tasks and resources to support and sustain the desired level of involvement of the older person. Improving practice will therefore need a commitment from residential care providers, funding and regulatory bodies, and adult protective services to challenge environmental and attitudinal barriers to the involvement of older people. In addition, education and support is needed for formal and informal carers in assessing capacity for a particular task and ensuring resources are available to support older people to make decisions or carry them out. Education and services that assist in recognising undue influence and resolving disputes between different players will also form part of an array of responses needed to improve practice.

Current and accurate knowledge of the principles underpinning legislation in relation to capacity and substitute decision making, attention to the attitudes and practices that restrict older people's involvement, and

resources to support innovative practice in residential care are urgently needed. The first steps are to recognise what constitutes inclusive practice in this contentious area of care provision and to develop the resources needed to support such practice. The challenge is to develop a range of practices around assisted and substitute decision making that truly reflect the diverse needs and interests of older people. Listening to the voices of people in their 'fourth age' and therefore treating them as citizens requires special effort (Scourfield 2007). This entails avoiding broad assumptions with respect to older people's interest and capacity to be involved in decision making about their finances and property and instead rising to the challenge of finding ways to represent older people in all their diversity.

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NOTES

1 In presenting the interview data, the formatted paragraphs are direct quotations, with the authors' glosses in square brackets. Some short direct quotes are embedded in the main narrative.

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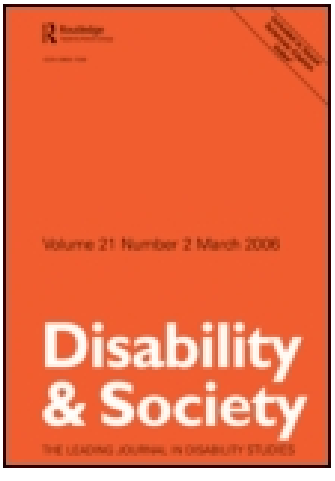

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'Mate crime': ridicule, hostility and targeted attacks against disabled people

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CURRENT ISSUES

'Mate crime': ridicule, hostility and targeted attacks against disabled people

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A common understanding of the term 'hate crime' involves opportunistic street crime and physical assault. The perpetrators do not usually have a relationship with their victims, although they may be known to live within the same neighbourhood. There are similarities between these types of targeted attacks against disabled people and people in other identity groups, such as BME communities, lesbians and gay men, transgender people. The term 'mate crime', is a play on the term 'hate crime', and refers to considered actions against disabled people at the hands of someone, or several people that the disabled person considers to be their friends, or they may be relatives. There does not seem to be a comparable set of hostile acts against the other identity groups who may be subjected to 'hate crime'. Acts of 'mate Crime' are acts of cruelty, humiliation, servitude, exploitation and theft. The occurrences of cruelty and servitude indicate that what is currently being termed 'mate crime', has more in common with domestic violence than 'hate crime' which is perpetrated by people with whom there is no relationship beyond acquaintance.

Keywords: disabled people; vulnerability; relationships; violence

Introduction

The usefulness of a concept of crime that is motivated by negative constructions of perceived difference has been questioned because it may lead to a 'special needs' approach which reinforces, rather than alleviates cultural differences. Yet treating people as if they are all the same does not challenge stereotypes, equalise people's situation, nor challenge cultures that maintain systems and practices that create and perpetuate exclusion (Grattet and Jenness 2001). The terms 'hate crime' and 'mate crime' are not ideal so they will be used in inverted commas; the paper will concentrate on the concepts rather than the terms. Few incidents of disablist 'hate crime' are recorded so there is uncertainty about what is happening. However there is a growing body of evidence, and growing media interest, raising the profile of disablist 'hate crime'.

'Hate crime' or 'mate crime'?

Disability Now's website has a dossier of disability 'hate crimes', giving brief descriptions of 51 incidents of hostility against disabled people. The largest group in

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the dossier are 31 people with physical impairments, followed by 13 people with learning difficulties, comprising 42 men and 12 women. (Disability Now 2010). Adding another two men with learning difficulties who died following targeted attacks gives evidence of 53 incidents (one incident involved two people).

Only two of the incidents were treated as 'hate crimes' by police; in 10 cases people were described as vulnerable. Thirteen incidents involved the death of the individual; 5 of these were murders, and one manslaughter. There were 27 incidents of theft and 23 of assault. Fourteen attacks were noted to have followed earlier repeated attacks. Ten people were tipped out of their wheelchair or scooter. Nine perpetrators were 'friends' or relatives; they were most likely to be involved with people with learning difficulties. It seems people with learning difficulties were most likely to die, be robbed, and held captive, whilst wheelchairs users are likely to be tipped out of their wheelchairs and robbed.

Attacks and theft where the perpetrator and victim share domesticity ('mate crime') have been included in cases described as 'hate crime' yet there are distinguishing features between the two sets of events:

(1) 'Hate crime' – violent attacks that are perpetrated by 'outsiders', not a part of the disabled persons household, or outsiders may enter the home purely to carry out the attack. There is little or no relationship between the perpetrators and the disabled person, they may be recognised as living in the area, but there is no reciprocal arrangement or inter-dependency. The disabled person does not welcome any part of any relationship there may be. These may be opportunistic attacks, or may be long term, repeated, sustained attacks. Examples include Francecca Hardwick. Brent Martin, Colin Greenwood, and Christine Lakinski (SCOPE, UKCDP, and Disability Now 2008), David Askew (Jenkins and Naughton 2010).
(2) 'Mate crime' – the hostile acts of perpetrators who are 'insiders', sharing domesticity to some degree, there is a mutual relationship. The disabled person may cling to the relationship, wanting the hostility to stop but welcoming the company and feeling part of a family or group. These situations are not opportunistic, they are calculated. Disabled people in these situations are less likely to complain to the police or other authorities because they consider the perpetrators to be their friends, they may justify the violence. This includes Kevin Davies, Steven Hoskin and Raymond Atherton (House of Lords 2008, 14), and Michael Gilbert (Sugden 2010).

The Crown Prosecution Service does not use the term 'mate crime' commenting that it is likely to cause confusion (Crown Prosecution Service [CPS] 2010a). Yet there are clear differences that warrant separate consideration.

Cultivating vulnerability

These events could be viewed as one person having control over another. However there is the context of a culture that creates and maintains structures and practices that disable and exclude people with impairments. This promotes a view that disabled people are worthy of contempt and hostility (Walker 2010). Further illustrated by one of the murderers of Brent Martin who said, 'I am not going down for a muppet' (SCOPE, UKCDP, and Disability Now 2008, 29). Furthermore, disablist jokes are still

considered good material for high profile comedy in a way that racist and homophobic jokes are no longer.

Perceptions that attacks are motivated by perceived vulnerability, and the language of perceived vulnerability, add to the problem of lack of recognition (CPS 2010b). Locating motivation with vulnerability is superficial; vulnerability simply makes it easier to carry out acts of hostility (Waxman 1991).

Yet disabled people may find they need to appear vulnerable, dependent, and grateful in order to get the support they need, and are forced into a situation and a form of behaviour. This is linked to the cultural expectation that disabled people will have a 'carer' to take responsibility for them (Morris 1993). Some carers have devoted their lives to looking after someone; this may become their main purpose and status in life. In the media and in social policy carers seem to be heralded as saviours of disabled people and the social care system.

This provides a situation that allows carers and pseudo-friends, if they are so minded, to:
take control of:

- where the disabled person lives;
- who they live with;
- when they get in or out of bed;
- when they may use the toilet;
- what they wear;
- if they get out of the house;
- who they are friends with, and when or if they have contact; and
- what and when they eat.

control behaviour or punish by:

- knowingly leaving equipment and other items out of reach;
- knowingly making the home inaccessible;
- withholding personal care; and
- withholding medication.

take advantage of a situation for personal gain by:

- making fraudulent use of blue car parking badges;
- making the motability car their own, whilst the disabled person does not get to use it; and
- claiming carer's allowance, but not actually supporting the disabled person.

These are ways for one individual to have power over another, which are done by ordinary people, in ordinary homes. These activities may not be considered to be unreasonable behaviour by those carrying them out, the disabled person themselves, or others. These activities would not be considered crimes by many and can easily be carried out without recourse to violence or even argument.

Relationships and domesticity

A key feature of 'mate crime' is the disabled person's desire for relationships and friendship. Raymond Atherton seemed to have been:

> befriended by groups of teenagers who abused his kind, gentle nature and exploited his vulnerability. … They damaged his [Atherton's] house, took his money and ate his food. … 'But because of his vulnerability, he couldn't say no to the people who came to his door, even though he knew he might end up being assaulted or his property damaged. When anything happened he couldn't name the visitors who assaulted him.' Hemingway [the police officer who led the enquiry] says she felt that Atherton would 'rather have their company than no one's'. (Carter 2007)

The desire for a relationship of some sort, the grooming and the servitude bear many of the hallmarks of domestic violence. 'Mate crime' is not always sexual partner violence. However the particular situation of disabled women living with domestic violence is noteworthy: 'It is important to be aware that, proportionally, many more disabled women are abused than non-disabled' (Hague et al. 2008, 83). The links with 'mate crime' are particularly evident for disabled women in domestic violence situations:

> A number of the women said they were made to feel, and indeed often felt, that, because of their impairments, they were undeserving of a relationship and should be grateful. … Interviewees who were in same sex relationships in particular had often been disbelieved and denied help. (Hague et al. 2008, 17–18)

The reliance on others at home for support is particularly marked:

> The women's narratives extensively illustrate intense and painful vulnerability to, and dependence on, their abusers for everyday tasks. They also emphasised their isolation, inability to leave their abusers (due in part to the limited availability of support services), and also their lack of educational or employment opportunities. (Hague et al. 2008, 16)

Hague et al. (2008) also found evidence of control of finances being taken to buy alcohol and or drugs, whilst disabled women were denied prescriptions and items for personal care.

Organisational response

The disabled people discussed would probably be described as having 'mild' or 'moderate' learning 'disabilities', physical or sensory impairments. It is unlikely they would have reached the attention of services because they would not meet the eligibility criteria of critical or substantial need. Inflexibility in social care also severely limits choice and control, as Ruth Bashall commented in *Getting away with murder* the portability of social care packages is essential in moving away from violent home life. (SCOPE, UKCDP, and Disability Now 2008, 24). Furthermore, disabled women need the right support in order to escape abuse:

> Women who directly employed abusive PAs found it difficult to criticise or 'discipline' them while they were dependent on them for care. The absence of adequate professional support led to much anxiety and some women were afraid their funding would be cut back if they reported difficulties with their PA. (Hague et al. 2008, 19)

Disabled people's organisations do not pay a great deal of attention to domestic violence, whilst women's refuges do not pay much attention to violence against disabled women and few are accessible to women with mobility impairments.

Reducing the incidence of 'mate crime'

Several things need to happen to change the dominant culture which currently allows these situations and events to happen. The media needs to take disablism seriously and not allow disablism to dominate, disablism (not impairment or the experience of disability) needs to be the butt of jokes. Putting disability comedy into the control of disabled people who ridicule disablism would go a long way towards culture change. There needs to be change within the criminal justice system and community safety systems which recognise that hostility toward disabled people, which is triggered by a perception of vulnerability, is a complication of hatred. Personalisation, which puts power and control with disabled people, will go a long way to shift the dominant expectation of dependence. The right peer support mechanisms need to be in place to send a clear message that, given the right circumstances, disabled people are not vulnerable and dependent. The development of disabled people's organisations in the Department of Health's user led organisation programme can also go a long way to shifting the culture toward disabled people being in control.

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