

The role of individual and social factors in the prevalence and experiences of making financial decisions for others

Dr Craig Sinclair Prof. Nic Cherbuin Scientia Prof. Kaarin J. Anstey

Wednesday July 5th, 2023













Imagine...

- Imagine that an older person you know well, perhaps a family member, has had a sudden serious illness or injury, or has a rapid deterioration in an existing dementia.
- In addition to managing appointments with health professionals and thinking about ongoing care and support, everyday financial decisions are becoming more difficult.
- Discussions with a residential aged care provider have made it clear there will be a substantial financial outlay in order to get admission. It may involve selling the person's house. A succession plan is also needed for the person's business, which is under threat of liquidation.
- There is a will in place, but nobody has ever discussed whose role it would be to make financial decisions if these were required. Or how to go about doing this.
- There is a history of disagreements within the family about managing family assets.
- ... and you are the one who has to make the decisions...



Background

- Substitute decision-making is a meaningful role, often undertaken by family members or trusted friends, for a person with impaired decision-making ability
- Can involve health/lifestyle and/or financial/legal decisions
- It is also associated with uncertainty, distress (Fetherstonhaugh et al, 2019) and post-traumatic stress (Wendler et al 2011)
- Convention on the Rights of Persons with Disabilities and human rights-based approaches to legal capacity
- Theoretical typology of surrogate/substitute decisionmaking (Tunney et al, 2015)
- Bargaining hypothesis (Yusof, 2015) vs Division of labour hypothesis

| Article | men tia |
|---|--|
| "Did I make the right decision?": The difficult and unpredictable journey of being a surrogate decision maker for a person living with dementia | Demoto 2019, Vel. 16(5) 160-161 ③ The Autorich(3) 2017 Article rease guideline sageplo.com/pormuls/permission DOI: 10.1177/1473 J0012172188 pournals.sageplo.com/homel/dem SAGEP |
| Deirdre Fetherstonhaugh and Linda McAul La Trobe University, Melbourne, Australia | iffe |
| Christopher Shanley Western Sydney University, Sydney, Australia; Ingham Institute for Applied Medical Research, Sydney, Australia | |
| Michael Bauer La Trobe University, Melbourne, Australia | |
| Elizabeth Beattie Queensland University of Technology, Brisbane, Australia | |
| Abstract Many people living with dementia eventually lose the capac will rely on another person – a surrogate decision maker – to important – especially with the increasing prevalence of d decision maker is understood and supported. This qualitativ 4 surrogate decision makers of persons living with den telephone interviews were conducted over six months in becoming the only – or main – surrogate decision maker; decision maker; dealing with the stress of making decisi | o make decisions on their behalf. It is ementia – that the role of surrogate re study explored the experiences o tentia in Australia. Face-to-face and 2014. Five themes were identified growing into the role of surrogate |
| Corresponding author: Linda McAuliffe, Australian Centre for Evidence Based Aged Care (ACEBJ 3086, Australia. Email: Innculiffe@Jarrobe.edu.au | AC), La Trobe University, Melbourne, Victoria |

Financial Substitute Decision-Making



Substitute Decisions

A substitute decision is a decision made on behalf of a person under a financial management order. The legal effect of a substitute decision is the same as if the person had made the decision themselves.

We make substitute decisions in your best interests. Our staff take into consideration the financial reasons for making a substitute decision as well as promoting your independence, increasing your quality of life and strengthening your relationships with friends, family and the community.

Substitute decision making policy

In making substitute decisions for our clients, NSW Trustee & Guardian follow the principles set out in section 39 of the NSW Trustee and Guardian Act 2009. We also make substitute decisions in accordance with the NSW Trustee & Guardian Decision Making Policy.

Outlined below are the general principles under section 39 of the NSW Trustee and Guardian Act 2009:

- (a) The welfare and interests of people with impaired decision making ability should be given paramount consideration
- (b) Their freedom of decision and freedom of action should be restricted as little as possible
- (c) They should be encouraged, as far as possible, to live a normal life in the community

4

Ref: NSW Trustee & Guardian

Types of financial substitute decision-making

- Attorney (appointed through a Power of Attorney)
- Private financial manager (appointed by a court or tribunal)
- Private trustee company
- NSW Trustee & Guardian

| | An enduring power of attorney is a legal document that allows you (the 'principal') | | | | |
|---|--|--|--|--|--|
| Complete this form by writing your responses on the lines. Clauses with options are to be completed by placing a tick in the appropriate box and ruling through those options that do not apply. | to nominate one or more persons (referred to as an attorney) to act on your behalf. An enduring power of attorney gives the attorney the authority to manage your legal and financial attains, including buying and selling rele latter, batters and other assets, operating your bank accounts and spending money on your behalf. | | | | |
| | The attorney's power continues even if for any reason you lose the mental capacity to manage your own affairs. Once you lose mental capacity you cannot revoke this power of attorney. If you want the power of attorney to cease if you lose mental capacity, use the General Power of Attorney form. An attorney under an enduring the Capacity of the Capacity form. | | | | |
| These margin notes are not sart of the prescribed form and can be removed. | power of attorney cannot make decisions about your lifestyle or health; these decisions can only be made by a guardian (whether an enduring guardian appointed by you or a guardian appointed by the Guardianship Tribunal or the Supreme Court). | | | | |
| Please refer to the Powers of Attorney Fact Sheet that accompanies this form for more information. The | The Prescribed Witness Certificate must be completed. Before acting as your attorneys, the attorneys (including any substitute attorneys) must sign the acceptance section. | | | | |
| Powers of Attorney Fact Sheet is also available from the Land and Property information website at | Please read the Important Information set out at the end of this document. It includes notes to assist in completing this document and more fully explains the role and responsibilities of an attorney. | | | | |
| Principal fou, the person who ippoints the attorney. | 1. Appointment of attorney by the Principal | | | | |
| | | | | | |
| The Attorney The person you nominate o look after your legal ind financial affairs. | [insert full name and address]. | | | | |
| four attorney may also be a company or other organisation such as the ISW Trustee and Guardian. | appoint | | | | |
| fou can appoint more than | | | | | |
| ne attorney. If you appoint nore than one attorney, it | and also appoint | | | | |
| may be useful to appoint people who can work cooperatively and in your best interest. | | | | | |
| | | | | | |
| | | | | | |



Financial Substitute Decision-Making

- Guardianship and Public Trustee agencies report
 on profiles of Financial Administration Orders
- While in the past intellectual disability was the primary reason for Guardianship Orders, dementia is now the most prominent disability group (Chesterman, 2013). Mainly due to demographic trends.
- Very little is known about the prevalence and experience of financial substitute decision-making at a community level.
- National inquiries have also recognised the potential for financial substitute decision-making to enable elder mistreatment and abuse – raising the importance of understanding this practice.

| Australian Government Australian Law Reform Commission | |
|---|--|
| | Elder Abuse— A National Legal Response |
| | FINAL REPORT |
| | |
| | |
| ALRC Report 131 | May 201 |

Ref: Australian Law Reform Commission (2017)

Research Questions

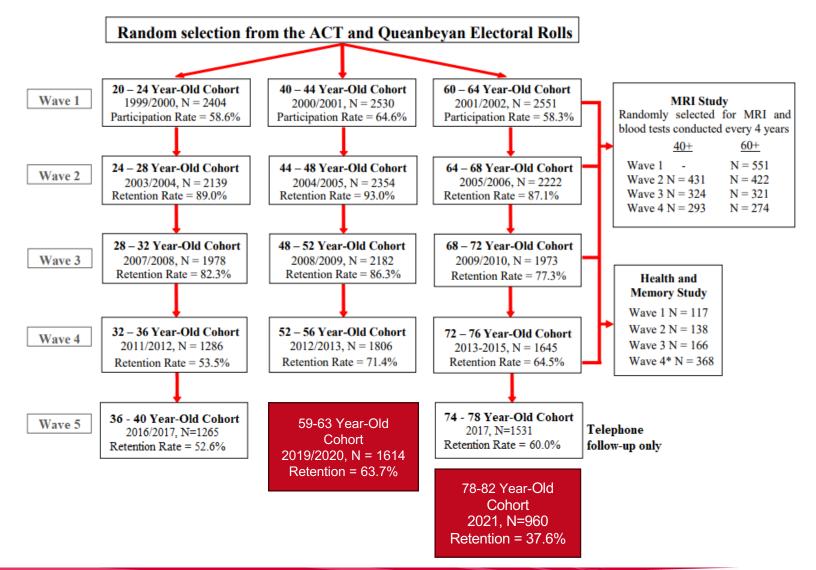
Describing the practice of financial substitute decision-making

- What is the estimated population prevalence of making a financial substitute decision for another person?
- Who typically makes financial substitute decisions?
- Who are financial substitute decisions made for?
- Under what authority are financial substitute decisions made?

Experiences associated with financial substitute decision-making

- Is the role of financial substitute decision-maker associated with higher household financial responsibilities?
- To what extent do financial substitute decision-makers experience
 - confusion/lack of information?
 - stress?
 - arguments/conflicts with others?
- And what factors are associated with these experiences?

Personality and Total Health (PATH) Longitudinal Cohort Study





Personality and Total Health (PATH) Longitudinal Cohort Study 40+ cohort Wave 5, 60+ cohort Wave 6

Financial Substitute Decision-Making Questions

'In the time since your most recent PATH survey, have you been required to make FINANCIAL decisions for someone else, due to their inability to make these decision/s?'

'Who did you make financial decisions for?'

'In what capacity did you make financial decisions?'

'I have received clear information about my role and responsibilities as a financial decision-maker'

'I found it stressful to make decisions for someone else'

'Being the decision-maker for someone else exposed me to arguments (and/or conflict with others)'



Methods

Analysis drew on:

- 40+ Wave 5 cohort (N = 1412, surveyed online)
- Sub-sample of the 60+ Wave 6 cohort (N = 960, phone) who opted-in to an additional postal survey (n = 633)
- Population sample weights (Wave 1) used to calculate weighted prevalence estimates
- Bivariate associations tested with Pearson's correlation and chi-square
- Hierarchical multivariable linear/logistic regression to control for demographic and socio-economic covariates
- An analysis plan was pre-registered at https://osf.io/9grj8/



Prevalence of financial substitute decision-making

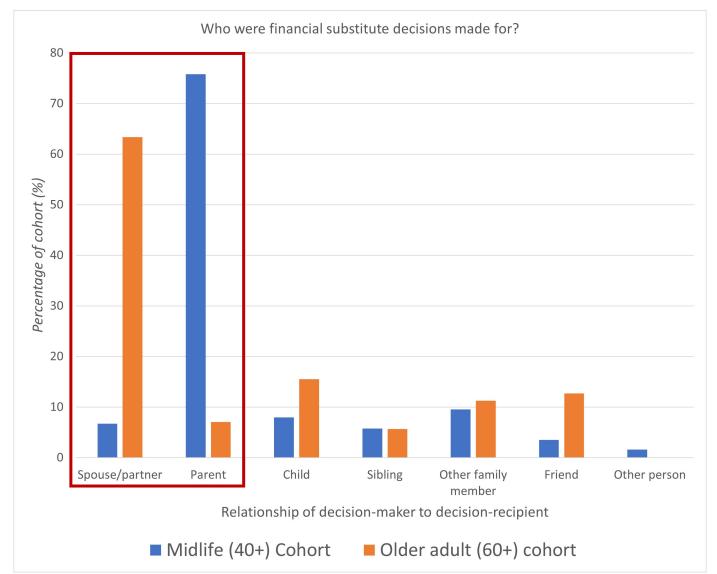
'In the time since your most recent PATH survey, have you been required to make FINANCIAL decisions for someone else, due to their inability to make these decision/s?'

| 40+ cohort : 5 year prevalence | Hence the cohorts were analysed |
|--|---------------------------------------|
| 60+ cohort : 3 year prevalence | separately for quantifying prevalence |

| Cohort | Crude Prevalence | Weighted Prevalence |
|--------------|------------------|---------------------|
| 40+ (5 year) | 314/1412 (22.2%) | 21.7% |
| 60+ (3 year) | 71/620 (11.5%) | 11.4% |



Who are financial substitute decisions made for?



CCOCCENTRE OF EXCELLENCE IN POPULATION AGEING RESEARCH

Who are the people acting as financial substitute decision-makers?

| Characteristic | Prevalence | Test Statistic | Prevalence | Test Statistic | | |
|---|---|---|---|---|--|--|
| | 40+ Cohort (N=14 | 12) | 60+ Cohort (n=620) | | | |
| Gender | Male: 156/664 (23.5%) Female: 158/748 (21.1%) | χ ² (1 df) = 1.01, <i>p</i> = .31 | Male: 43/341 (12.6%) Female: 28/277 (10.1%) | χ^2 (1 df) = 0.71, p = .40 | | |
| Marital Status | Married: 205/969 (21.2%) Single*: 108/441 (24.5%) | χ² (1 df) = 1.76, ρ = .18 | Married: 47/397 (11.8%) Single*: 24/218 (11.0%) | χ^2 (1 df) = 0.03, p = .86 | | |
| Education | 0-10 years: 2/12 (16.7%) 11-12 years: 14/103 (13.6%) 12+ years: 263/1149 (22.9%) | χ^2 (2 df) = 4.96, p = .08 | 0-10 years: 0/14 (0%) 11-12 years: 7/64 (10.9%) 12+ years: 64/536 (11.9%) | χ ² (2 df) = 1.93, <i>p</i> = .38 | | |
| Self-reported financial hardship | Yes: 44/192 (22.9%) No: 270/1220 (22.1%) | χ ² (1 df) = .02, <i>p</i> = .88 | Yes: 1/14 (7.1%) No: 69/599 (11.5%) | χ^2 (1 df) = 0.01, p = .93 | | |
| Household income / week (\$AUD) | Less than \$650: 14/85 (16.5%) \$650 - \$1749: 127/556 (22.8%) More than \$1750: 151/655 (23.1%) Don't know/ Refused: 20/112 (17.9%) | χ ² (3 df) = 3.25, p = .35 | \$575 or less: 2/89 (2.2%) \$576 - \$1700: 48/385 (12.5%) More than \$1700: 16/102 (15.7%) Don't know/ Refused: 5/35 (14.3%) | χ² (3 df) = 9.77, ρ = .02* | | |
| Household financial strain (responsibility %) | Fully (100%): 130/521 (25.0%) 75% responsible: 54/262 (20.6%) 50% responsible: 91/404 (22.5%) 25% responsible: 33/185 (17.8%) Not at all (0%): 6/39 (15.4%) | χ ² (4 df) = 5.77, p = .22 | Fully (100%): 50/321 (15.6%) 75% responsible: 7/98 (7.1%) 50% responsible: 11/102 (10.8%) 25% responsible: 1/57 (1.7%) Not at all (0%): 1/34 (2.9%) | χ ² (4 df) = 15.0, p = .005** | | |
| Financial literacy | 100% correct: 72/275 (26.2%) 75% correct: 122/557 (21.9%) 50% or less correct: 120/557 (20.8%) | χ^2 (2 df) = 3.20, p = .20 | 100% correct: 18/173 (10.4%) 75% correct: 32/254 (12.6%) 50% or less correct: 21/194 (10.5%) | χ^2 (2 df) = 0.59, p = .74 | | |

ARC CENTRE OF EXCELLENCE IN POPULATION AGEING RESEARCH

CC

Who are the people acting as financial substitute decision-makers?

- Other than weak effects of household income and household financial responsibility (in the 60+ older adult cohort), demographic factors were not associated with financial substitute decisionmaking.
- A situation/experience that can affect a wide variety of people, particularly during mid- and later-life stages.
- Mid-life financial substitute decision-making is predominantly for parents (76%). Older adult financial substitute decision-making is predominantly for spouse/partners (63%).
- So what are the implications of exposure to this role?



Is financial substitute decision-making associated with increased household financial responsibilities?

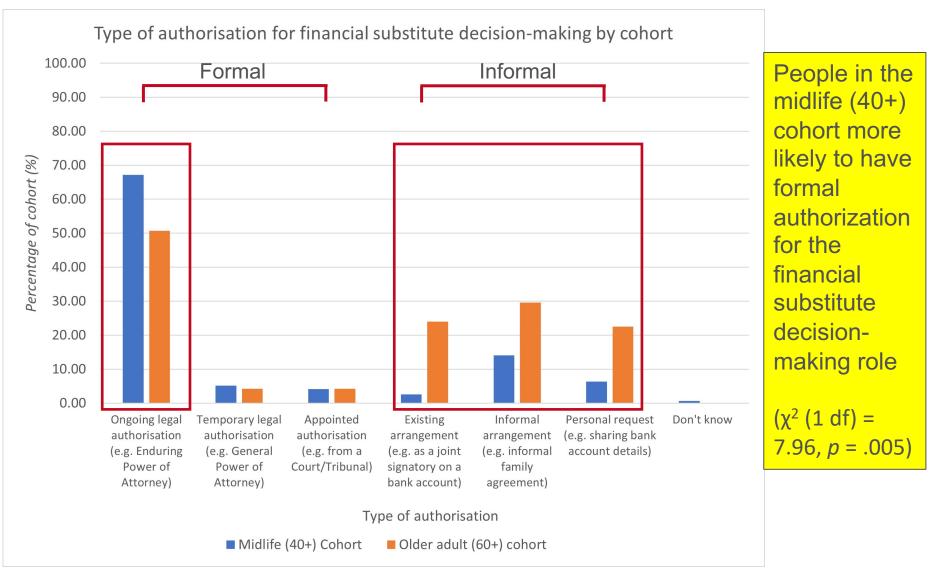
| | Univaria | Jnivariate Demographic | | raphic | Socio-economic | | |
|--|-------------|------------------------|--------------|----------|----------------------------|----------------|--|
| Predictor | B (SE) | р | B (SE) | р | B (SE) | p | |
| Financial substitute decision- maker (Yes) | 0.19 (0.07) | .006** | 0.19 (0.06) | .002** | 0.17 (0.06) | .008** | |
| Age | | | 0.02 (0.02) | .31 | 0.02 (0.02) | .33 | |
| Gender (Male) | | | 0.15 (0.05) | .009** | 0.16 (0.06) | .011* | |
| Marital Status (Single) | | | 1.14 (0.05) | <.001*** | 1.13 (0.05) | <.001*** | |
| Cohort (60+) | | | -0.26 (0.33) | .44 | -0.23 (0.35) | .50 | |
| Gender (Male) * Cohort (60+) | | | 0.28 (0.11) | .008** | 0.26 (0.11) | .016* | |
| Education (11-12 years) Education (12+ years) | | | | | 0.72 (0.31) 0.72 (0.31) | .026* .022* | |
| Self-reported financial hardship (Yes – sometimes, or often) | | | | | 0.19 (0.09) | .03* | |
| | | | | | E - 52.2 | n < 0.01 | |

Yes – even while controlling for a range of demographic and socio-economic factors

 $F_{(9,1840)}$ = 53.2, p < .001 R squared = 0.20

COOL ARC CENTRE OF POPULATION AGEING RESEARCH

Under what authority are financial substitute decisions made?



CCOCCENTRE OF EXCELLENCE IN POPULATION AGEING RESEARCH

Which factors are associated with 'decisional distress' in the financial substitute decision-making role?

| | Lacked information (14%) | | Experience Stress (36%) | | Argument/Conflict (36%) | |
|--|--------------------------------------|--------------|--------------------------------------|--------------|--------------------------------------|--------------|
| Predictor | OR (95% CI) | р | OR (95% CI) | p | OR (95% CI) | р |
| Age | 1.06 (0.85-1.32) | 0.62 | 1.09 (0.93-1.28) | 0.27 | 0.80 (0.67-0.96) | 0.02* |
| Cohort (60+) | 0.22 (0.00-19.9) | 0.51 | 0.11 (0.00-2.62) | 0.17 | 0.01 (0.00-7e ¹³) | 0.79 |
| Gender (Male) | 1.40 (0.68-2.91) | 0.90 | 0.44 (0.26-0.73) | 0.002** | 1.59 (0.95-2.68) | 0.08 |
| Education (11-12 years) Education (12+ years) | 0.12 (0.00-9.12) 0.33 (0.01-17.2) | 0.35 0.58 | 0.70 (0.02-20.8) 1.10 (0.04-29.4) | 0.82 0.95 | 0.37 (0.00-11.2) 0.78 (0.00-21.0) | 0.52 0.87 |
| Marital status (Single) | 1.60 (0.77-3.25) | 0.20 | 1.00 (0.60-1.64) | 0.99 | 0.88 (0.52-1.48) | 0.63 |
| Financial Hardship (Yes, sometimes/ often) | 0.48 (0.14-1.39) | 0.21 | 1.31 (0.63-2.71) | 0.47 | 2.70 (1.30-5.78) | 0.009** |
| Deciding for a spouse/partner Deciding for a parent | 0.55 (0.15-1.84) 0.86 (0.38-1.97) | 0.34 0.71 | 0.60 (0.23-1.51) 0.65 (0.36-1.16) | 0.28 0.14 | 0.60 (0.21-1.60) 1.17 (0.64-2.14) | 0.32 0.61 |
| Authority (No formal authority) | 4.22 (2.06-8.76) | <.001*** | 0.89 (0.50-1.57) | 0.70 | 0.92 (0.51-1.65) | 0.61 |
| Eysenck – Neuroticism | 1.02 (0.90-1.14) | 0.78 | 1.01 (0.93-1.10) | 0.80 | 1.03 (0.94-1.12) | 0.55 |
| Eysenck – Extraversion | 0.96 (0.87-1.05) | 0.35 | 0.99 (0.92-1.06) | 0.70 | 1.09 (1.01-1.17) | 0.02* |
| Eysenck - Psychoticism | 1.07 (0.87-1.32) | 0.50 | 1.11 (0.95-1.29) | 0.18 | 1.07 (0.92-1.25) | 0.36 |
| Pearlin Mastery Scale | 0.92 (0.83-1.02) | 0.11 | 0.96 (0.89-1.02) | 0.21 | 0.95 (0.88-1.02) | 0.16 |
| Financial literacy (Lusardi et al) 75%-100% correct | 0.88 (0.43-1.84) | 0.73 | 0.87 (0.53-1.43) | 0.57 | 0.99 (0.60-1.68) | 0.99 |

ARC CENTRE OF EXCELLENCE IN POPULATION

Implications

- Financial substitute decision-making is prevalent in mid-life and older adulthood regardless of demographic or socio-economic factors.
- In mid-life decisions are mostly made for parents.
- In older adulthood decisions are mostly made for spouse/partners.
- Financial substitute decision-making is associated with increased household financial responsibilities.
- A substantial minority (~10-40%) experience distress in making substitute financial decisions.
 - Those who use informal approaches experience increased risk of lacking information about the financial substitute decision-making role.
 - Those experiencing financial hardship more likely to experience arguments or conflict in the financial substitute decision-making role.
- Findings may assist in targeted outreach and education about financial literacy and financial substitute decision-making.

Thankyou!

Craig Sinclair: c.sinclair@unsw.edu.au, @csinclair28

Acknowledgements

PATH study Wave 5 (40+ cohort) and Wave 6 (60+ cohort) was funded by the Australian Research Council Centre of Excellence in Population Ageing Research (CE170100005) and a NeuRA Discovery Grant awarded to Prof. Kaarin Anstey.

- Professor Anstey is funded by ARC Laureate FL190100011.
- Dr Sinclair is funded by NHMRC Project Grant 600283
- We thank Tanya Layton, the PATH study team, PATH interviewers and PATH participants

References

Australian Law Reform Commission. (2017). Elder Abuse - A National Legal Response (ALRC Report 131). Sydney: Australian Law Reform Commission Retrieved from https://www.alrc.gov.au/publication/elder-abuse-a-national-legal-response-alrc-report-131/

Fetherstonhaugh, D., McAuliffe, L., Shanley, C., Bauer, M., & Beattie, E. (2017). "Did I make the right decision?": The difficult and unpredictable journey of being a surrogate decision maker for a person living with dementia. *Dementia*, 18(5), 1601-1614. doi:10.1177/1471301217721862

Tunney, R. J., & Ziegler, F. V. (2015). Toward a Psychology of Surrogate Decision Making. *Perspectives on Psychological Science, 10(6), 880-885. doi:10.1177/1745691615598508*

Wendler, D., & Rid, A. (2011). Systematic review: the effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine*, 154(5), 336. doi:10.7326/0003-4819-154-5-201103010-00008

Yusof, S. A. (2015). Household Decision-Making in Malaysia: The Ethnic Dimension. Social Indicators Research, 124(1), 283-293. doi:10.1007/s11205-014-0782-8

