## ORIGINAL ARTICLE



# Self-managed aged home care in Australia - Insights from older people, family carers and service providers

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#### Abstract

This paper presents findings from the evaluation of an Australian trial of self-managed home aged care. The self-management model was codesigned by advocacy organisation COTA Australia, consumers and service providers. The primary aim of the evaluation was to examine whether self-management improved consumers' perceptions of their choice, control, and wellbeing. The secondary aim was to examine whether provider prior experience with self-managed packages significantly influenced consumers' perceptions of choice, control and wellbeing, thereby confounded trial effects. A pre-test post-test quasi-experimental design and mixed-methods design were used to collect data over nine months in 2018-2019. The pre-trial methods and findings have been published. The post-trial evaluation replicated the pre-trial data collection method of an online survey (n = 60) and semi-structured telephone interviews with consumers (n = 9), family carers (n = 13), and consumers and carers jointly (n = 2), totalling 24 interviews. Semi-structured telephone interviews were also conducted with CEOs and senior managers from each of the seven providers (n = 14). Three providers had prior experience supporting self-management. Parametric and non-parametric tests examined the statistical data. Qualitative data were analysed thematically and framed according to selfdetermination principles and ecological systems theory. Both datasets demonstrated that consumers reported greater choice and control at post-trial than pre-trial. This finding was not affected by providers' prior experience with self-management; therefore, it was not a confounding factor. Participants reported improved wellbeing in interviews, however this was not reinforced statistically. Key desirable features of self-management included greater autonomy and control over spending, recruiting support staff and paying lower administration fees. There was no evidence of increased risks or fraud. The research limitations included a small sample size, convenience sampling with providers recruiting interview participants, no control group and differences in trial implementation. The findings support the expansion of self-management opportunities and more comprehensive evaluations that use mixed methods.

#### **KEYWORDS**

aged care, autonomy, empowerment, home care, risk, self-determination, self-directed support

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## 1 | INTRODUCTION

In Australia, government-funded home support for older people with complex needs is provided through 'home care packages'. Since 2015, all packages have been 'consumer directed' (Australian Government, 2020). An approved aged care service provider ('provider') holds the funds, the consumer has the right to choose and change their provider, know their budget, and be actively involved in selecting services. A small number of providers give older people, or their representative, the option to self-manage. The term 'self-manage' has a similar meaning to the term 'self-direct' (Duffy, 2018). It means that recipients have the authority to manage their budget, employ staff, and purchase supports and services directly.

COTA Australia, an advocacy organisation representing older Australians, was funded by the Australian Government to design and evaluate a self-management model. Seven approved aged home care providers from across Australia joined the trial and recruited 103 consumers to self-manage their home care package.

The self-managed model was co-designed by COTA Australia, the providers and several consumers and family carers. Features of the model were that participants could recruit support workers and other staff, pay award wages, use a debit card, and pay lower administration fees to providers. Further details of the model, the resources developed to support self-management, and their final report are available on the COTA Australia website (COTA Australia, 2019). A detailed description of the evaluation design and pre-trial findings showing the expectations of participants have been published (Laragy & Vasiliadis, 2020). This paper reports on the post-trial data, their analysis, and interpretation.

The pre-trial data analysis showed that participants wanted to self-manage because they expected that greater choice and control would overcome many frustrations that they experienced under the traditional home care model and would achieve better outcomes (Laragy & Vasiliadis, 2020). Their high expectations left the independent evaluators wondering if these expectations could be met, and if participants were aware of possible challenges and risks. Australia's Royal Commission into Aged Care, Quality, and Safety (2019), and the Australian Law Reform Commission (2017) reported widespread financial, physical, psychological, sexual and emotional abuse of older people living at home, often inflicted by family members. The post-trial interviews were alert to these concerns.

This paper reports on consumer experiences and satisfaction with the self-management model. The findings presented are part of a larger body of unpublished evidence that included the carers' experiences of self-management independent of the consumer. Due to word limits, these findings are not presented in this article.

### 1.1 | Theoretical frameworks

Self-determination theory underpins consumer directed care (Quality of Care Principles, 2014), and the design of the COTA Australia self-management trial (COTA Australia, 2019). Self-determination means

#### What is known

- Australian government-funded home support packages can now be self-managed, including care-related purchases, staff and services.
- Self-management can improve older people's perception of their physical health, and their wellbeing when living at home.
- Participants' high expectations at pre-trial were met.
   Greater self-determination through autonomy and control over spending, choosing support staff and paying lower administration fees were reported.
- There was no evidence of fraud or increased risks throughout the trial.

#### What this paper adds

 Self-managed home aged care can be an efficient system that provides self-determination, personalised care and reduced reliance on primary care services.

having autonomy and agency in decisions and choices about one's life, planning and achieving one's goals (Stancliffe et al., 2020). Research demonstrates a significant positive association between self-determination and physical health, wellbeing and thriving of older people living at home (Lämås et al., 2020; Tang et al., 2020).

Bronfenbrenner's (1995) ecological systems theory was used to structure the qualitative findings because its micro, meso and exo-systems explore factors relevant to self-management. Bronfenbrenner's early theory (Rosa & Tudge, 2013) illustrates the interconnectedness of the personal, social, institutional and physical environments. Bronfenbrenner (1995) defined *microsystems* as personal relations within the family and others. *Mesosystems* are relations among two or more microsystems, for example between the person, their provider and support workers. *Exosystems* are settings that impact on people without them being personally involved. For example, the provider's policies, practices and costs. *Macrosystems* are broad economic, social, education, legal, and political systems that determine the structures, beliefs and characteristics of a society. While acknowledging their importance, macrosystems are not discussed in this paper.

This study aimed to examine the effectiveness of COTA Australia's self-management model in home aged care with the following research questions:

- Could the trial model significantly improve consumers' perceptions of choice and control of their package from baseline to trial completion?
- Could the trial model improve consumers' subjective wellbeing from baseline to trial completion?

Provider preparedness for delivering self-managed packages emerged during data analysis as a potential mediator of the

effectiveness of the trial. Therefore, a third research question was added:

Did the provider's prior experience and preparedness for delivering self-managed packages statistically significantly influence (that is confound) trial outcomes for consumers?

### 2 | METHOD

RMIT University's Human Research Ethics Committee approved the study (CHEAN B 21296-01/18). The study conformed to the Australian 'National Statement on Ethical Conduct in Human Research' guidelines (National Health & Medical Research, 2018). All interviewees signed an ethics consent form.

## 2.1 | Participants

## 2.1.1 | Survey

Sixty of the 99 pre-trial baseline surveys could be matched with post-trial surveys. Approximately 20% of participants withdrew during the trial because they moved to residential care, died, found no service differences and for unknown unspecified reasons.

Nineteen consumers completed the post-trial survey independently. Forty-one consumers completed the survey with assistance from their family carer, or their family carer completed the survey on their behalf. Surveys completed by consumers independently showed no statistical differences to those completed with assistance or where a family carer acted as their proxy.

Consumers were aged from 53 to 100 years, with a median age of 82 years. Family carers acting with or on behalf of the consumer were aged from 38 to 97 years. Further demographic information of all participants is available in Table 1.

## 2.1.2 | Interviews

Pre-trial, nine interviews were conducted with independent consumers, two with a consumer and family carer (both husbands), and seven with family carers only (wife, male partner, four daughters, son) (n=18). One independent consumer reported being of First Nations background. Post-trial, interviews were repeated with all interviewees except one who was not available. Seven additional participants were interviewed. These were one consumer and six family carers (wife, three daughters and two sons), including one daughter who withdrew her father from the trial (n=24). At post-trial there were nine semi-structured telephone interviews with consumers, 13 with family carers, and two with the consumer and the carer together.

Post-trial interviews were conducted with CEOs and senior managers from each of the seven providers involved (n = 14).

TABLE 1 Demographic information of consumer participants in the trial

the trial		
	n	%
Gender		
Male	20	33
Female	40	67
Age group		
Under 70	8	15
70s	16	30
80s	21	40
90+	8	15
State		
VIC	23	38
WA	20	33
TAS	9	15
QLD	5	8
NSW	3	5
Education		
High School (Years 7–9)	3	5
High School (Years 10–12)	12	20
Trade or technical certificate	8	13
University or tertiary studies	37	62
Diversity		
CALD	6	10
LGBTIQ	0	0
ATSI	2	3
Veteran	1	2
Home care package level		
Level 1 (low support needs)	3	5
Level 2	25	42
Level 3	9	15
Level 4 (high support needs)	23	38

## 2.2 | Procedure

Two independent university-affiliated researchers conducted the evaluation. The pre-trial method, which was described in detail in a previously published article (Laragy & Vasiliadis, 2020), was repeated post-trial. The trial was undertaken over nine months during 2018–2019.

Recruitment into the trial was undertaken jointly by *COTA Australia* and the participating providers. Consumers who were identified as having the capacity to self-manage were invited to participate in the trial. The surveys were pilot tested by the consumer and the informal carer on the project's Steering Committee.

An online survey was completed at pre-trial and post-trial. A subgroup of participants were invited to participate in semi-structured telephone interviews with the independent researchers at pre-trial and post-trial. The survey and interviews asked about the consumer's experience and satisfaction with utilising their package prior to and during the trial. Post-trial interviews were also conducted with representatives of the providers.

# 2.2.1 | Survey

All survey questions were developed by the researchers with input from the COTA Australia project team and Steering Committee. The questions were written to closely align with the goals and functions of traditional home aged care support (for baseline comparison) and those of the model under trial. Items from the POET survey (In Control & Lancaster University, 2017) on subjective wellbeing were used because they had been used successfully to study self-management in the United Kingdom.

The baseline and post-trial online surveys asked participants to indicate the consumer's satisfaction with their package regarding their level of choice and control, knowledge about its use, and positive and negative expectations and outcomes of self-management using a 7-point Likert scale from 'strongly disagree' to 'strongly agree'. Statements about perceived and experienced risks of self-management were rated on a 5-point Likert scale. The internal reliability of the scales ranged from  $\alpha=0.79$  to  $\alpha=0.91$ , indicating very good to excellent reliability.

## 2.2.2 | Interviews

The providers recruited trial participants for semi-structured telephone interviews. Interviews were conducted by the independent researchers and ranged from 30 to 60 min duration. Notes were taken during and immediately after interviews. The post-trial interviews asked about influential outcome factors, satisfaction of pre-trial expectations, and experience of risks. Providers were asked about differences from past practices, challenges of implementation, and any advantages, disadvantages or risks for themselves or consumers. The researchers took detailed notes and recorded quotations during and immediately after interviews.

## 2.3 | Data analysis

## 2.3.1 | Quantitative

Preliminary Wilcoxon Signed-Ranks Tests found few and very small differences between surveys completed by consumers independently and surveys completed with the assistance of family carers. Because there was no evidence of significant completion method bias, the surveys were analysed collectively regardless of whether consumers had responded independently or with assistance.

To address the first two research questions, Wilcoxon Signed-Ranks Test compared the means of survey scales and items from pre-trial to post-trial because the differences in ratings were not

normally distributed (Tabachnick & Fidell, 2007). Pre-post comparisons of the summed scale scores plus individual items were analysed.

To address the third research question, two-way mixed analysis of variance examined whether provider experience interacted with pretrial-posttrial effects for each item.

IBM SPSS Statistics 26 analysed all statistics.

## 2.3.2 | Qualitative

Interview notes were first analysed with theoretical thematic coding, applying self-determination theory, then with inductive thematic coding (Maguire & Delahunt, 2017). The two interviewers reviewed and validated the coding and its interpretation to ensure trustworthiness of the findings (De Vaus, 2001). NVivo 10 was used to organise and analyse the data.

## 3 | FINDINGS

## 3.1 | Quantitative

# 3.1.1 | Comparison of pre-trial and post-trial surveys

These findings address research questions 1 and 2 by comparing pre-trial and post-trial survey answers.

### Quality of life

The summed total of seven items (Table 2) showed a significant improvement at post-trial. Examination of individual items showed that while there was improvement in all items, only subjective physical wellbeing reached statistical significance.

### Quality of support and information

The summed scale of nine items showed no significant pre-trial and post-trial difference. Tests of each scale item showed a statistically significant improvement in participant's satisfaction with the quality of support from their paid support worker from baseline, but the improvement was small.

## Financial autonomy and control

There was a significant improvement as measured by the summed score of these seven items. Tests of each scale item showed significant improvements in understanding self-management, expectations, and finances, and in having a method to make payments at their discretion.

## Possible relational and psychological outcomes

There was no significant difference as measured by the summed scale of these seven items. There was a significant reduction in concerns about risks, and lower agreement to a statement saying that relationships with providers improved. Table 3 shows

TABLE 2 Wilcoxon signed-ranks test medians and statistics of significance for between pre-trial and post-trial participant experience

Scale and item	Pre-trial median	Post-trial median	т	z	р
Quality of life	35	36.5	484	-2.40	0.016
My physical well-being is as good as it can be	5	6	253	-2.71	0.007
I do lots of things in my community	2.5	4	267	-1.53	0.126
My social wellbeing is very good	4	5	230.5	-1.40	0.161
My economic (financial) well-being is very good	4	5	328.5	-1.36	0.174
l enjoy my family and/or friends	6	6	150	-0.35	0.727
I am happy where I live	6.5	7	134	-1.40	0.161
I have choice and control over my everyday decisions	6	6	289.5	-0.16	0.869
Quality of support and information	53	54	593	-0.85	0.394
My views were included when my support/care plan was decided	6	6	304.5	-0.44	0.662
I can decide how the money in my home care package is spent	6	6	406	-0.06	0.956
I am satisfied with the quality of support from my case manager	6	6	237	-1.54	0.124
I am satisfied with the quality of support from my paid support workers	6	6	174.5	-2.16	0.031
I receive all the care and support I need	6	6	423.5	-0.85	0.394
I am responsible for choosing from where my services and supports are purchased	6	6	388.5	-0.57	0.572
I have all the information I need to make decisions about my care and support	5.5	6	251.5	-1.53	0.127
In general, I am satisfied with my home care package provider	6	6	363.5	-0.38	0.706
I am supported with dignity	6	7	269.5	-0.20	0.840
inancial autonomy and control	37	41	1,159	-3.26	0.001
I understand self-management and what is expected of me	6	7	62.5	-4.09	0.000
I have enough information to manage my package finances	5.5	6	231	-3.48	0.001
The services and supports I receive represent good value for money	5	6	300	-1.04	0.298
I need the support and input of my case manager	5	4	555	-1.01	0.311
I am clear about what I can and cannot spend my package funds on	5	6	335	-1.27	0.203
I have financial autonomy to make decisions about spending my package funds	6	6	263.5	-2.02	0.044
I have a method of paying (at my discretion) for services and items to meet my care needs	5	6	149.5	-3.68	0.001
Possible relational and psychological outcomes	53	54	593	-0.85	0.394
More money to spend on services and supports	6	6	362.5	-0.12	0.907
More stress <sup>a</sup>	3	2	372	-1.29	0.197
Positive changes in my relationship with my provider	6	5	287	-2.09	0.036
More risk <sup>a</sup>	4	6	700.5	-2.43	0.015
Positive changes in my relationship with my carer/family	6	5	657	-1.92	0.055
Fewer calls to my provider regarding finance and budget issues	6	5	665.5	-2.02	0.044
Positive changes in my relationship with my paid support workers	6	5	369	-0.81	0.419
Confidence to self-manage	38	37	607	-0.96	0.336
I can manage my home care funding	5	5	164	-1.48	0.138
I know what I can and cannot spend my package funds on	4	4	227	-0.44	0.660
I understand my clinical care needs and how to manage them	5	4	158	-0.25	0.806
I know how to employ suitable care staff to meet my needs	5	5	247	-0.66	0.512
I know how to set goals for my care plan	5	5	170.5	-1.33	0.183
I can navigate the aged care system	4	4	211.5	-1.27	0.206
Others may face these problems, but I don't expect they will apply to me/I can explain self-management to others	2	4	97	-4.60	0.000

<sup>&</sup>lt;sup>a</sup>A higher median score indicates less stress or less risk.

that consumers with experienced providers reported improved relationships.

#### Confidence to self-manage

There was no significant improvement in the summed score of these six items. An item relating to confidence with self-management in general did significantly improve.

# 3.1.2 | Confounding effect of service providers' experience

These findings address the third research question by examining whether pre-trial versus post-trial differences observed in the analyses above are lessened when the providers' level of experience and preparedness is accounted for in the analysis. The absence of a statistically significant interaction effect between these variables indicates that provider experience did not lessen the differences from pre-trial to post-trial. Even though provider experience with self-management was associated with a more positive consumer experience, it was not a statistically significant confounding factor in the evaluation of trial effectiveness.

An interaction effect was observed for only 7 out of 30 items. As shown in Table 3, three items relate to financial autonomy and control, three to possible relational and psychological outcomes, and one to quality of support and information.

Significant main effects were observed for provider's prior experience for 13 out of the 30 items, with consumers of experienced providers reporting more satisfaction than those with providers new to self-management. Consumers of less experienced providers were less likely to agree at post-trial that they experienced positive outcomes

Notably, there were interaction effects but no main effects showing significant pre-post difference for the items 'I have all the information I needed to make decisions about their care and support', 'More money to spend on services and supports' and 'Positive changes in my relationship with my paid support workers'. The providers' experience had a confounding effect on how these items were answered. Participants with experienced providers reported having more information and better relations with support workers, but not more money to spend.

#### 3.2 | Qualitative

The interview data showed that most participants embraced self-management and had positive outcomes. An unexpected finding was that three providers and nearly half the participants were self-managing prior to the trial. The trial resulted in few changes for the three experienced providers, apart from two offering a debit card for the first time, while the third did not offer a debit card despite it being offered in the COTA Australia trial model. Participants who

were previously self-managing made comparisons with prior case managed services, plus they spoke of the advantages of having a debit card. The findings are presented under three of Bronfenbrenner's (1995) headings – micro, meso and exo-systems.

## 3.3 | Microsystem

## 3.3.1 | Self-determination

Most participants welcomed self-management because it increased their choice, control and autonomy, and resulted in improved personal outcomes. The seven providers offered participants varying levels of autonomy as they implemented the trial model in different ways that reflected their service model and values. Three providers had extensive experience supporting consumers to self-manage, one had some experience, and three were new to self-management. Participants appreciated any move to self-management because it enabled them to be more self-determining.

We've had autonomy to spend money...make your own decisions and be able to execute it in a timely manner... The babysitting they used to do is unnecessary. ... It's been really great having that level of independence. I've enjoyed the trial. (Carer 1, daughter, with inexperienced provider)

Self-management encourages taking responsibility, independence, and community involvement... [It] allowed me to continue my independence to hire and train my own carers – it is beneficial to me. (Consumer 1, with experienced provider)

#### 3.3.2 | Improved outcomes

Many participants reported that self-management enabled them to better meet their personal needs, have more community access, and more funds to spend on services and supports.

I got out and did more things, was not restricted to being at home...Having more access to the community has been a godsend, for example going to class because of extra money and because I could pay Uber on the card.... Savings add up, a bit here and there. I buy from the supermarket [instead of a medical shop]. (Consumer 2, with experienced provider)

We have \$7,500 extra funds [per annum] because we are self-managing. (Consumer 3, with inexperienced provider)

TABLE 3 Two-way mixed ANOVA estimated marginal means and statistics of significance for interaction effect between pre-post trial and provider experience

	Pre-trial		Post-trial		
	Experienced providers	Less experienced providers	Experienced providers	Less experienced providers	
Scale and item	M <sup>a</sup>	M <sup>a</sup>	M <sup>a</sup>	M <sup>a</sup>	Statistics of interaction effect
Quality of life					
My physical well-being is as good as it can be	4.40	4.84	5.11	5.28	F(1,58) = 0.34 p = 0.564  eta = 0.006
I do lots of things in my community	3.23	3.32	3.34	3.76	F(1,58) = 0.40 p = 0.531  eta = 0.007
My social wellbeing is very good	3.94	4.68	4.51	4.60	F(1,58) = 2.11 p = 0.152  eta = 0.035
My economic (financial) well-being is very good	4.14	4.20	4.43	4.44	F(1,58) = 0.01 p = 0.919  eta = 0.000
I enjoy my family and/or friends	5.86	6.12	5.94	6.16	F(1,58) = 0.28 p = 0.868  eta = 0.000
I am happy where I live	5.80	6.48	6.14	6.48	F(1,58) = 1.78 p = 0.187  eta = 0.030
Quality of support and information					
I have choice and control over my everyday decisions	5.40	5.92	5.60	5.48	F(1,58) = 2.67 p = 0.108  eta = 0.044
My views were included when my support/ care plan was decided	6.09	6.40	6.28	5.84	F(1,55) = 3.40 p = 0.071  eta = 0.058
I can decide how the money in my home care package is spent	5.97	5.72	6.09	5.40	F(1,56) = 0.92 p = 0.342  eta = 0.016
I am satisfied with the quality of support from my case manager	5.31	5.42	5.79	5.67	F(1,51) = 0.26 p = 0.610  eta = 0.005
I am satisfied with the quality of support from my paid support workers	5.46	6.04	6.18	5.96	F(1,55) = 3.74 p = 0.058  eta = 0.064
I receive all the care and support I need	5.03	5.80	5.35	5.64	F(1,57) = 0.89 p = 0.351  eta = 0.015
I am responsible for choosing from where my services and supports are purchased	5.84	5.44	6.03	4.84	F(1,55) = 2.13 p = 0.150  eta = 0.037
I have all the information I need to make decisions about my care and support	4.91	5.52	5.85	5.04	F(1,56) = 8.44 p = 0.005  eta = 0.131
In general, I am satisfied with my home care package provider	5.78	5.83	5.94	5.38	F(1,55) = 2.44 p = 0.124  eta = 0.042
I am supported with dignity	6.16	6.17	6.38	5.83	F(1,53) = 1.69 p = 0.199  eta = 0.031
Financial autonomy and control					
I understand self-management and what is expected of me	5.97	5.40	6.64	5.92	F(1,56) = 0.320 p = 0.574  eta = 0.006
I have enough information to manage my package finances	5.53	5.08	6.53	5.24	F(1,57) = 4.94 p = 0.030  eta = 0.080
The services and supports I receive represent good value for money	5.38	4.96	5.19	4.68	F(1,57) = 2.23 p = 0.141  eta = 0.038
I need the support and input of my case manager	4.00	4.88	3.94	4.28	F(1,57) = 0.986 p = 0.325  eta = 0.017
I am clear about what I can and cannot spend my package funds on	5.15	5.16	5.82	4.92	F(1,57) = 3.052 p = 0.086  eta = 0.051
I have financial autonomy to make decisions about spending my package funds	5.44	4.76	6.18	5.00	F(1,57) = 7.110 p = 0.010 eta = 0.111
I have a method of paying (at my discretion) for services and items to meet my care needs	4.79	4.56	6.38	4.96	F(1,57) = 5.760 p = 0.020  eta = 0.092
Possible relational and psychological outcomes					
More money to spend on services and supports	5.88	5.24	6.06	4.96	F(1,56) = 7.931 p = 0.007  eta = 0.124
More stress <sup>b</sup>	2.85	3.24	2.24	3.40	F(1,57) = 2.184 p = 0.145  eta = 0.072

TABLE 3 (Continued)

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	Pre-trial		Post-trial		Post-trial		
	Experienced providers	Less experienced providers	Experienced providers	Less experienced providers			
Scale and item	M <sup>a</sup>	M <sup>a</sup>	M <sup>a</sup>	M <sup>a</sup>	Statistics of interaction effect		
Positive changes in my relationship with my provider	5.44	5.56	5.44	4.48	F(1,57) = 6.95 p = 0.011  eta = 0.109		
More risk	3.09	3.88	2.24	3.44	F(1,57) = 0.526 p = 0.471  eta = 0.009		
Positive changes in my relationship with my carer/family	5.62	5.08	5.32	4.32	F(1,57) = 1.015 p = 0.318  eta = 0.017		
Fewer calls to my provider regarding finance and budget issues	5.85	5.52	5.29	4.96	F(1,57) = 0.000 p = 0.998  eta = 0.000		
Positive changes in my relationship with my paid support workers	5.41	5.24	5.79	4.28	F(1,57) = 7.51 p = 0.008  eta = 0.116		
Confidence to self-manage							
I can manage my home care funding	5.41	5.24	5.79	4.28	F(1,55) = 0.028 p = 0.868  eta = 0.001		
I know what I can and cannot spend my package funds on	4.29	4.21	4.44	4.13	F(1,57) = 0.597 p = 0.443 eta = 0.011		
I understand my clinical care needs and how to manage them	4.56	4.17	4.56	4.17	F(1,56) = 0.000 p = 1.000 eta = 0.000		
I know how to employ suitable care staff to meet my needs	4.56	4.25	4.59	4.00	F(1,56) = 0.737 p = 0.394  eta = 0.013		
I know how to set goals for my care plan	4.47	4.04	4.65	4.25	F(1,56) = 0.012 p = 0.912 eta = 0.000		
I can navigate the aged care system	4.15	3.75	4.38	3.79	F(1,56) = 0.281 p = 0.598  eta = 0.005		
Others may face these problems, but I don't expect they will apply to me/I can explain self-management to others	3.12	2.96	4.55	3.83	F(1,56) = 1.593 p = 0.212 eta = 0.0028		

Abbreviation: ANOVA, analysis of variance.

## 3.3.3 | Risks

The pre-trial interviews showed that participants did not anticipate any personal or financial risks when self-managing. At post-trial, only one adverse incident was reported. A consumer bought a bag of garden potting soil using the debit card and was asked to refund the cost by a provider new to self-management. Another experienced provider allowed a similar purchase. Most participants were confident they could manage any risks.

[There might be] risk for others but not for me... They need to know what is allowed and what is not, what to use the card for and what not. If the system is simple, those without financial literacy still can self-manage. (Consumer 2, with experienced provider)

## 3.3.4 | Stress

Most participants found the administration bothersome and stressful initially, especially the debit card. Once familiar with procedures,

many found self-management to be less stressful than negotiating with providers. It tended to be easier for participants with experienced providers who had established administrative procedures. All participants interviewed planned to continue to self-manage beyond the trial.

Since swapping... [to self-management], my time dealing with provider issues was 90% less... It was a breeze, thank god. (Carer 4, son, with experienced provider)

Managing myself was so much better.... In the end it is less stress... [It] allowed me to take control... It would have driven me insane having someone else manage it. (Carer 5, daughter, with inexperienced provider)

## 3.3.5 | Family carers

Many family carers said self-management resulted in better relationships between the consumer and their family, and they benefitted when the consumer's needs were met. One husband said his health

<sup>&</sup>lt;sup>a</sup>Means are estimated marginal means of interaction effect between provider experience and pre-post tests, obtained from two-way mixed ANOVA analyses.

<sup>&</sup>lt;sup>b</sup>A higher mean score indicates less stress.

improved when his wife with dementia returned from a nursing home after he recruited suitable staff (Carer 2, husband).

I didn't want Mum going to a nursing home... ... Now everything is done just as Mum likes it. She's treated like a Duchess. (Carer 3, daughter, with experienced provider)

## 3.4 | Mesosystem

## 3.4.1 | Information and support

Participants needed clear information about procedures to understand their options and know the rules. Many had concerns about the debit card and becoming liable for repayments, a problem that one consumer experienced when purchasing potting soil. Most participants turned to their provider for advice before reading COTA Australia's resource kit or contacting COTA Australia's staff. Six of the seven providers offered some case management support, with the exception being one of the experienced providers.

It took 2 to 3 months to work out the ins and outs of self-management and now I'm fairly confident. (Carer 3, daughter, with experienced provider)

#### 3.4.2 | Debit card

There were initial technical difficulties registering the debit cards and uploading funds. While some participants abandoned it, others persevered and welcomed its convenience and opportunities to purchase products and medicines from cheaper stores. They were able to buy medical supplies online, buy incontinence pads from the supermarket, and use an Uber.

The card gave me independence.... I purchased much online. I was relaxed because I was not out of pocket...I could plan purchases according to my needs... it was fantastic... It was good for my mental health. (Consumer 4, with experience provider)

#### 3.4.3 | Recruitment

An important feature of self-management for many participants was being able to choose their support workers. This was seen as a great improvement on agency employed workers who were sometimes strangers arriving 'sight unseen', mismatched to their needs, having little English, and coming at unpredictable and inappropriate times. Inexperienced providers generally made few changes to their workforce arrangements and offered little choice. Experienced providers referred participants to online recruiting services, while

they conducted police and qualification checks. Nursing and aged care qualifications were important to some participants, while others looked for personal attributes and skills. Some consumers reported that carefully selecting workers enabled them to continue to live at home and they recruited local community members outside the aged care workforce. For example, a man resumed eating after his daughter recruited two local women who visited and cooked his favourite food. (Carer 5, daughter, with inexperienced provider).

[Self-management] allowed us to select the carers... dementia has made Mum racist, she was not nice to carers of African descent. (Carer 6, son, with experienced provider)

Some participants thought that support workers preferred to work for an individual consumer than for an agency because it gave both parties more flexibility, control, and a better personal relationship. A support worker, an older woman with no savings who did not want agency work, said to the participant 'you saved me'. (Carer 3, with experienced provider).

#### 3.5 | Exo-system

## 3.5.1 | Provider perspectives

Each provider implemented the *COTA Australia* self-management model in a way that reflected their values, business model and interpretation of self-management. The three providers with experience of self-management were strongly committed to consumer self-determination, and had integrated administration, recruitment, financial management and risk management systems. Their models changed little during the trial, apart from two introducing the debit card while the third did not. One experienced provider who introduced the debit card struggled to acquit the payments because their financial system did not have this functionality. The three providers experienced with self-management remained committed to its continuation. A representative comment was, 'It's not risky if we learn how to deal with problems' (Provider 1, experienced).

Two of the experienced self-management providers had a case management arm to their business. Consumers could move between the two arms and pay fees accordingly. One manager with both models said that support workers often preferred to work under self-management arrangements. They had more control over their working hours, generally a better relationship with their employer/consumer, and they were not tied to an agency roster where they 'rush in and out like on a conveyer belt'. (Provider 1, experienced).

Providers new to self-management faced major cultural and administrative changes.

We had to retrofit systems, it was difficult... it doubled my workload. Clients [i.e., consumers and carers] like it, fantastic to see it continue for them. But for others, clients need more training, and staff too. (Provider 6, inexperienced provider)

The four inexperienced providers had different reasons for trialling self-management. One CEO was strongly committed to self-determination principles and was transitioning the organisation away from being a traditional case managed model. A second provider offered self-management because of market demand and compliance with directions to offer greater choice and control. A third provider with some, but limited experience supporting self-management, had lost their self-management coordinator and was unsure of their position. The fourth provider had reservations about self-management and said:

'[aged care is] best done in conjunction with case managers... Sometimes they [consumers] don't know what they don't know. They need guidance to follow government guidelines'. (Provider 7. inexperienced).

This quote illustrates the staff member's reservations about older people self-managing because it was thought they did not have the capability to do so. It is unclear how widespread these discouraging views were across the organisation.

## 4 | DISCUSSION

The study found that consumers perceived having greater choice and control of their home aged care package at the end of the trial. Support for improvements to subjective wellbeing were evidenced in the interviews but not statistically. Contrary to the researchers' concerns, the statistical examination of differences in choice, control and wellbeing from pre-trial to post-trial were not lessened by variation in providers' prior experience with self-management and their implementation of the COTA Australia trial model. All participants across all age ranges and providers planned to continue to self-manage.

The qualitative interview data showed overwhelming support for self-management because it offered greater choice, control and flexibility. The quantitative data showed moderate improvements in choice, control and flexibility from pre-trial to post-trial. This may be because consumers from three providers had been receiving a form of self-management when the trial began, which had not been anticipated. Participants with the three experienced providers reported in interviews few large changes during the trial, apart from most using the debit card. They liked self-management and welcomed the debit card. An interesting finding was that each provider implemented the COTA Australia self-management model differently, with the greatest differences being between inexperienced and experienced providers.

Although COTA Australia provided a detailed model of self-management, each provider implemented the model slightly differently based on their experience of self-management and their business model. Four providers were trialling self-management for the first time. Six providers offered reduced case management fees

to consumers who self-managed because they, or their carer on their behalf, shared the administration responsibilities. The seventh provider was awaiting the results of the trial before determining if fees will be lowered. Two providers with experience of self-management also had a case management arm to their business and consumers could move between the two arms and pay fees accordingly. The three providers with experience of self-management had well established self-management models and clear business aims to offer self-management at reduced costs compared to providers with case-management service experiences.

The overall positive findings are consistent with those from self-management studies in the UK (Think Local Act Personal, In Control, & Lancaster University, 2014), and the United States (US) (Robert Wood Johnson Foundation, 2015). The US Cash & Counseling program consisted of numerous programs conducted from 1996 to 2009 in 15 states involving 13,500 people of all ages. The randomised control studies showed better health outcomes for older consumers, reduced unmet needs, and improved quality of life for both consumers and carers. These findings suggest improvements within' microsystems (Bronfenbrenner, 1995), compared to traditional provider-managed services.

Woolham et al. (2017) studied people aged over 75 years in the UK and found no significant outcome differences between the self-management and control groups. Those self-managing valued having greater choice and control, particularly choosing support workers, and developing trusting relationships. However, having greater choice did not translate into better measurable outcomes in physical, social and psychological wellbeing. The UK authors reported that funding for self-management was low and only covered basic care with no discretionary spending. These differences in funding may have contributed to the poorer outcomes than were found in the current study. Despite reporting these limitations, they concluded that older people would be better off not self-managing and instead having specialist gerontological workers and consumers co-produce person-centred, nonpersonal budget-based care and support. Our findings contradict this conclusion and support self-management.

Our positive findings also contrast with conclusions drawn from a meta-analysis that showed having choice is not always beneficial for older people who self-manage, particularly as they find legal and administrative responsibilities burdensome (FitzGerald Murphy & Kelly, 2019). Choice is a complex concept in public policy. Clarke et al. (2007) defined three antagonisms limiting choice: inequality and inadequate resources; retention of decision-making power by bureaucrats and professionals; and prioritising of risk management over individual wishes. Our findings show that participants were inherently aware of these factors and that self-managing helped them to address all three. They had more funds to spend on services and supports, and sufficient autonomy to decide how to spend the funds and what risks to take. Once participants learnt how to use the debit card, the level of burden they experienced was minimal. Participants who worked with providers who had experience of self-management found it easier because there were well-developed financial administrative procedures.

A seminal United Kingdom (UK) study by Glendinning et al. (2008) found that older people tended to find self-management stressful. However, they reported that older people often commenced self-management at a time of crisis when support services were initiated, and there were poor organisational support arrangements. As these conditions are notably different to the COTA Australia trial, it is not surprising that outcomes were different. While not suggesting that everyone will want to, or is capable of self-managing, the study highlights the benefits of self-managing for some.

Bronfenbrenner's (1995) mesosystem highlights relationships between participants and their providers and support workers. Table 2 shows that participants improved their relationships with providers and support workers, preferred to choose their support workers, and benefited from using the debit card. Support workers were not interviewed in this study and their views still need to be ascertained. A feature of Bronfenbrenner's ecological systems theory is the interconnections between microsystems forming the mesosystem. This helps to understand how participants' experience of the trial was affected by differences in the implementation by each provider.

Bronfenbrenner's (1995) ecosystem puts a focus on the provider's policies and practices. Although the study was not designed to look for differences between new and experienced providers, these emerged as a major finding in the interviews and were confirmed by statistical analyses (see means in Table 3). Participants with experienced providers indicated improved relationships with their provider and better outcomes at post-trial, even though they were self-managing previously. However, participants with inexperienced providers indicated poorer outcomes compared to pre-trial in several areas.

It is conjecture based on the interview data that participants with experienced providers were satisfied they were utilising the trial's self-management potential, while those with inexperienced providers considered that their provider could offer more. This theory needs to be tested. Despite these differences, the statistical data showed that self-management contributed more to participants' outcomes than provider experience. This suggests that the benefits of self-management overcome the challenges experienced by providers new to the model.

Provider interviews revealed major attitudinal differences between experienced and inexperienced providers of self-management. The differences have parallels with findings from an Australian study conducted when consumer directed care (CDC) was introduced (KPMG, 2015). Providers were classified into 'early adopters and leaders', 'proactive' and 'reactive or resistant'. The differences impacted on consumers in ways that resonated in this study, and provider experience should be considered in future research.

# 5 | RESEARCH LIMITATIONS AND FUTURE RESEARCH

The research limitations include having a small sample size; convenience sampling with providers recruiting participants; no control

group; and inconsistent implementation of self-management across providers. There was no evidence of recruitment bias of interviewees because the survey and interview findings largely aligned.

Future research could compare examples of self-management with traditional provider-managed models; consider the provider's experience with self-management; use established psychometrically robust measures; conduct a longer-term trial to provide insights into the effectiveness of self-management as consumers' needs change; compare the experiences of consumers and carers from different age groups and ethnic backgrounds in a larger sample; and examine support' experiences of self-management when employed by the consumer or an agency, their rates of pay, flexibility of hours and work satisfaction. First Nations people were purposely included in the study. However, as the numbers were small, more work is needed to understand how self-management can work to the advantage of First Nations people.

#### 6 | CONCLUSION

This paper adds clarity to a field where there are conflicting findings. Rather than asking if additional choice and control offered by self-management results in better outcomes, we need to ask what factors contribute to self-management resulting in better outcomes. Consumers and their family carers need information, clear guidelines and supportive service providers. The COTA Australia (2019) website provides useful guides and toolkits for both consumers and providers to assist them navigate the challenges of self-management. Looking at the findings through Bronfenbrenner's (1995) ecological systems theory lens, transitioning from agency managed services to consumer controlled, self-managed services requires profound organisational change. Professionals used to managing services for older people have to learn new roles as facilitators and supporters, while providers have to develop new financial and data management systems to manage individual accounts. It is hoped that our findings will assist this transition.

#### ETHICS APPROVAL STATEMENT

RMIT University's Human Research Ethics Committee approved the study (CHEAN B 21,296-01/18).

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### **CONFLICT OF INTEREST**

The authors have no conflict of interest.

#### DATA AVAILABILITY STATEMENT

Research data are not shared.

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