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Consumer expectations of self-managing aged home care packages in Australia

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Conflict of Interest

The authors have no conflict of interest.

Abstract

This study investigated the expectations of older people who chose to participate in a self management trial of home aged care packages conducted by COTA Australia. Empowerment theory is used to interpret the findings. All Australian home aged care support packages are delivered using a consumer directed care (CDC) model, and most are managed by an aged care provider. The COTA Australia trial gave older people the opportunity to self-manage their package and have

more control over spending and less constraints on its use. This study examined three questions: i) what motivated the older person, or an informal carer acting on their behalf, to participate in the self-managing trial; ii) what outcomes they expected; iii) and what was their attitude towards risk. The trial was conducted over nine months in 2018-19. Seven registered home aged care providers from six Australian states and territories recruited 103 consumers to the trial, with having an informal carer act on their behalf. Online questionnaires with consumers (n=103) and informal carers (n=66), and 18 semi-structured interviews showed that older consumers and their informal carers had high expectations that self-management would result in: increased choice and control and more flexible use of funds; lower administration fees and more money to spend on services and supports; improved relations with service providers; and the opportunity to select support staff. Participants wanted clear information and guidelines and support from their provider. While wanting to have more control and be empowered, few respondents noted concerns about possible risks. This finding raises questions about consumers' awareness of risks that are documented in the literature, and it challenges providers to balance risk management with facilitating independence and autonomy.

What is known about this topic

- Opportunities for self-managed home care aged packages are increasing in many countries
- Little is known about why some older people want to self-manage
- Findings from the Australian Royal Commission into Aged Care showing widespread abuse and neglect place responsibilities on self-management programs to ensure that older people are not exploited.

What this paper adds

- Insights into why some older people and/or their informal carer want to self-manage their home care package, their expectations and their attitudes to risk
- An awareness that service providers and policy makers have heightened responsibilities to manage risks because consumers see few potential risks

in self-management, and to do so while not disempowering consumers nor stifling their independence and autonomy.

Introduction

All Australian home aged care packages have been delivered on a 'consumer directed care' (CDC) basis since July 2015 (Australian Government, 2017), as legislated in the *Living Longer, Living Better, Aged Care Act 2013* (Commonwealth of Australia, 2013). The 2019 *Quality Standards* (Aged Care Quality and Safety Commission, 2019) require approved providers to promote choice and independence, and to support consumers with taking risks "to enable them to live the best life they can" (S.1.3.d). These standards require a substantial change from traditional service delivery and they encourage the exploration of innovative approaches that include older people self-managing CDC packages (Australian Institute of Health and Welfare, AIHW, 2019). There are various models of self-management in home aged care and no universal definition. A consistent feature is that consumers have more control and flexiblility compared to agency managed CDC packages.

This paper reports on a study that examined participants' motivations for joining a self-management trial of home aged care packages, their expectations and their attitudes towards risk. The model is detailed below under the heading *Trial design*. The findings are interpreted using empowerment theory and examine individual concepts of 'meaning', 'competence', 'self-determination' and 'impact' (Hur, 2006).

COTA Australia's trial of their self-managed home aged care model was conducted during a period of widespread criticism of home aged care and residential service provision in Australia, including reports of neglect and abuse. The Royal Commission into Aged Care Quality and Safety detailed consumer experiences of extreme abuse and neglect (2019a), difficulties in negotiating the aged care system (2019b), and insufficient resources (2019a). The reports were discussed at

length in the media (Beech, 2018) and consumers were likely aware of them when participating in the trial. The Australian Government is under pressure to provide efficient and safe aged care supports that are responsive to consumer needs (Productivity Commission, 2017).

CDC in Australia

Prior to the introduction of CDC, the government block-funded selected aged care providers and clients usually remained with their initial provider. Since 2015, CDC funding has been allocated in a consumer's name and held by an approved aged care provider chosen by the consumer (Australian Government, 2019). Funding is 'portable' and consumers can change providers. While these changes are a move towards a market model, competition has been limited and service availability varied across regions (KPMG, 2015). Only 13% of provider outlets offered the opportunity to self-manage in 2018 (AIHW, 2019).

CDC was trialled prior to it being universally implemented in 2015. Studies of these trials and the early implementation of CDC found little change from traditional service provision. Participants were unaware of choices in service delivery and costs and they gratefully accepted whatever services were offered (Gill & Cameron, 2015; Gill, Bradley, Cameron & Ratcliffe, 2018; Day, Thorington, Hunter, Summons, van der Riet, Harris, Maguire, Dilworth, Jeong, Bellchambers, Haydon and Higgins, 2018). Inflexible service design and negative staff attitudes inhibited change (Gill & Cameron, 2015; Day et al., 2018). One inhibiting factor was case managers and other staff being concerned that they would lose power in their relationships with consumers (You, Dent & Doyle, 2017). Interestingly, consumers mirrored the attitudes of staff they worked with, be that positive or negative (Orpin, King, & Boyer, 2016).

Studies found positive as well as negative findings. Some consumers expectated that CDC would give them more control and financial autonomy, the opportunity to choose their support workers and to save unspent funds for future use (Kaambwa, Lancsar, McCaffrey, Chen, Gill, Cameron, Crotty & Ratcliffe, 2015). At times senior managers supported the principle of clients being empowered, while their coordinators and support workers felt

threatened (Payne & Fisher, 2019). These workers were concerned that consumers with knowledge of their package budget and costs would become more authorative and demanding and treat them as employees instead of professionals who knew what was best. Notably, most studies did not include the views of older people who were self-managing. This gap is addressed in the current study.

Previous self-managing trials

A search of peer reviewed and grey literature identified four documented Australian aged self-managing trials. They had different designs but similar findings. The earliest was the Victorian *People at Centre Stage* (PACS) trial (Ottmann, Laragy, & Allen, 2012). Three aged care providers supported 87 clients to co-design an 'enabling/restorative' model of self-management where participants chose the level of responsibility they undertook. Building on the PACS trial, 'CHOICES in CDC Aged Care" (Ottmann, Millicer, & Bates, 2015) trialled a model of self-management involving seven aged care service providers and 195 clients. This trial offered self-management in regional/ rural areas to First Nation consumers and to Greek consumers. The objectives of this trial were to: develop a CDC model responsive to the needs of diverse communities; develop training packages for case managers and care coordinators who supported people in these communities; and evaluate the effectiveness of the CDC model. A third study, which was also linked to the PACS trial, was undertaken by the Brotherhood of St Laurence (BSL) (Simons, Kimberley & McColl Jones, 2016). They evaluated their ongoing self-managing program with a sample of 45 consumers. In the fourth study, an Australian aged care provider evaluated their ongoing self-management program during 2014-16. This involved 12 staff and 43 consumers (Peterson & Buchanan, 2016, unpublished).

Despite differences in program design, findings from these four studies show consistent benefits and challenges. Consumers welcomed having authority to make decisions, being able to bypass case managers and contact brokered services and workers directly and having flexibility when purchasing services and supports. Their active involvement and agency left them feeling more capable and less lonely (Ottmann, Laragy, & Allen, 2012; Ottmann, Millicer, & Bates, 2015; Simons, Kimberley & McColl Jones, 2016). The fourth

study by Peterson and Buchanan (2016, unpublished) measured quality of life outcomes and found that self-management resulted in higher quality of life outcomes, more self-efficacy and resilience and reduced pressures on families. No consumers or providers in any study reported an increase in risks or negative consequences. Common challenges for programs were providing timely and appropriate information without overwhelming consumers, and developing consistent and effective administration and financial procedures. There were reports of case managers with oversight responsibilities feeling ill-prepared to support self-management (Peterson & Buchanan, 2016, unpublished), and of senior managers' and case managers' attitudes creating barriers to the successful implementation of self-management (Laragy & Allen, 2015).

In the four studies cited above, no mention was made of consumers' motivations, their expectations of self-managing or their attitudes towards risk. It is important to understand consumers' motivations and expectations to implement self-management programs successfully. This paper fills this gap and uses empowerment theory (Hur, 2006) to understand consumers' perceptions of self-managing.

Risks of self-management

In many studies, despite staff reporting concerns that self-management would expose older consumers to risks of abuse, fraud and exploitation, no adverse events were reported (Laragy & Allen, 2015; Ottmann, Laragy, & Allen, 2012; Ottmann, Millicer, & Bates, 2015; Peterson & Buchanan, 2016, unpublished). While these findings are encouraging, reports of widespread financial, physical, psychological, sexual and emotional abuse from the Royal Commission into Aged Care (2019b), and the Australian Law Reform Commission (2017), make it imperative that self-managing programs have mechanisms to prevent abuse and neglect.

International reports found little evidence of heightened risk to consumers in self-management programs. Two English studies found that adverse events did occur, however their prevalence was no higher than in agency managed programs (Manthorpe & Samsi 2013; Ismail et al., 2017). The authors cautioned against imposing safeguards that would

infantilise older consumers and stifle their agency and self-determination. A meta-analysis of self-managing evaluations concluded that proactive policies can prevent fraud and abuse (Sciegaj et al., 2016). One factor that appeared to mitigate against abuse was having older people select their services and support workers (Dowson & Duffy, 2011).

The COTA Australia trial included the use of debit cards. Proponents of self-management in England argued against using debit cards in self-managed programs (Independent Living Strategy Group, 2017). This was not because consumers might be at risk or misuse them, but because they gave funding authorities online access to accounts, which they considered too intrusive.

To better understand older people's motivations for wanting to self-manage their home aged care package, this study addressed the following research questions: i) why did consumers, or their informal carer on their behalf, volunteer to participate in the self-managing trial; ii) what were their expectated outcomes; iii) and what were their attitudes towards risk.

Empowerment theory (Hur, 2006) provides a useful framework for reviewing consumer attitudes towards self-management. It has two interrelated dimensions: personal empowerment and collective empowerment. This paper considers the four components of personal empowerment: meaning, competence, self-determination and impact.

Design of the home aged care self-managed model

COTA Australia drew on international literature and worked collaboratively with aged care providers, consumers and informal carers to design their home aged care self-managed model and information resources for the trial. The trial was advertised nationally and recruited seven approved home aged care providers from six states and territories. COTA Australia offered a toolkit and support to all providers in the trial. A detailed description of COTA Australia's model can be found on their website (COTA Australia, 2019). The core components of the model were that the participant: developed a care plan with their provider that specified their needs and preferences and set parameters for spending package

funds; decided where and how to recruit staff, for example from an employment hire company or by advertising online; managed support staff; approved payments; monitored spending and made sure funds were spent according to home care legislation and their care plan. The trial included the use of a debit card to purchase goods and services. Each provider implemented the model in ways that reflected their culture. COTA Australia had expected that service providers would commence self-management during the trial. However, four of the seven providers were offering varying degrees of self-management options prior to the trial.

The trial was conducted over 9 months from June 2018. A Steering Committee that guided the trial's development was comprised of a consumer, an informal carer and a senior representative from each of the seven approved providers. The Steering Committee and additional agency managers attended three face-to-face full day workshops and had monthly teleconferences to exchange information. Two COTA Australia project staff and an independent aged care consultant offered consumers unlimited telephone and email support. Additionally, the consultant rang each consumer twice during the trial to provide information and assistance.

Research method

Participants

Of the 103 consumers and informal carers who commenced the trial, 99 completed a baseline questionnaire. Consumers were aged from 53 to 100 years, with a median age of 82 years. Informal carers were aged from 38 to 97 years. As indicated in Table 1, 32% of baseline questionnaires were completed independently by the consumer, 17% with an informal carer, and 51% by an informal carer representing the consumer. The duration participants had previously been receiving a home care package was: for 0-5 months (n=25), 6-12 months (n=15), 1-2 years (n=19), 2-5 years (n=24), and over five years (n=16). The number of participants self-managing prior to the COTA Australia trial is unknown because this situation was not anticipated and data were not collected. This issue was followed up in

interviews and 50% (9 of 18) reported self-managing elements of their home care package prior to the trial.

[Insert Table 1 about here]

Participants' demographic details summarised in Table 1 were comparable with national statistics. The sample included a slightly higher representation of older women (68%) than the national average (AIHW, 2018). The sample's slightly higher representation of First Nations people possibly reflects the purposive sampling strategy used (4% vs. 3%, respectively) (Australian Bureau of Statistics (ABS), 2016a). Only 10% of participants were from a culturally and linguistically diverse (CALD) background, compared to approximately 25% of home aged care recipients nationally (AIHW, 2016). Consumers and informal carers had a substantially higher level of education than their peers (see Table 2) (Australian Bureau of Statistics, 2012).

[Insert Table 2 about here]

Procedure

The seven participating providers invited consumers from their service to participate in the trial. Providers were asked to recruit a purposive sample (Patton, 1990) of First Nation and CALD consumers that was broadly representative of their clientele. Some providers advertised widely while others approached consumers who had expressed interest in self-managing.

The providers distributed information materials prepared by COTA Australia. Each provider recruited between nine and 29 participants. While no incentive or reimbursement for participation was given, some providers allowed participants to pay reduced agency fees during the trial. There were no consequences for non-participation, that is, services continued unchanged for those who did not participate. RMIT University's Human Research Ethics Committee approved the study, which conformed to the Australian 'National Statement on Ethical Conduct in Human Research' guidelines (National Health and Medical Research, 2018).

Questionnaires

Service providers emailed a link to the questionnaire on the Surveymonkey platform to consumers who had consented to participate. Ninety-nine completed baseline questionnaires were analysed. Informal carers who answered on behalf of, or together with, the consumers were asked to respond from the consumer's point of view. An additional informal carers questionaire was also provided, which is not discussed in this paper. The questionnaires were pilot tested by the consumer and the informal carer on the project's Steering Committee.

Interviews

Each provider nominated and recruited at least two participants for interviews, resulting in 18 interviews with participants from six states. With permission, providers passed participant contact details to the COTA Australia project team who scheduled the interviews. Semi-structured telephone interviews of 30-60 minutes were conducted by two university-affiliated project researchers who were independent of COTA Australia. Nine interviews were conducted with independent consumers, two with a consumer and informal carer (both husbands), and seven with informal carers only (wife, male partner, four daughters, son). One independent consumer reported being of First Nation background. The researchers took detailed notes during interviews and typed them immediately afterwards.

Instruments

Questionnaire

The questionnaires collected demographic data about health and sociocultural diversity (see Table 1), and used scales to record statements about well-being, understanding of service options, satisfaction with services prior to entering the COTA trial, perceptions of risk when self-managing, and outcomes expected. Each scale comprised seven to 11 statements, which participants answered on a seven-point Likert scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Statements about possible risks were rated on a five-point Likert scale ranging from 1 (*very unlikely*) to 5 (*very likely*). Each item on the questionnaire offered the option to add comments. All questions were developed by the researchers with input from

the COTA Australia project team except the wellbeing items, which drew on the English 'Personal Outcomes Evaluation Tool (POET)' survey (In Control & Lancaster University, 2017).

Interviews

The interview schedule mirrored the questionnaire and gathered contextualised information about motivations, expectations and perceptions of risk when self-managing. The researchers had access to the questionnaire results prior to the interviews and explored responses in depth during the interviews.

Data analysis

Quantitative

Questionnaire data were summarised using descriptive analyses. Independent Samples Mann-Whitney U-Tests compared answers given by consumers and carers independently. This test was used because the assumptions of normality were not met for parametric tests. Analyses were conducted using IBM SPSS Version 26.

Qualitative

Interview notes were first coded into pre-determined themes derived from a literature review. Key themes included: control, choice, empowerment, independence, and risk (see Table 5). Salient emergent themes were incorporated into the final thematic code set (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.

Findings

Tables 3 and 4 show participants' expectations of positive outcomes and potential risks of self-managing. The data show that most participants expected positive outcomes, including less reliance on their provider, lower administration fees, more money to spend on services and supports, and improved relationships with their provider, informal carer, family and paid support workers. A minority expected to experience more stress or risks.

[Insert Table 3 about here]

When consumers and informal carers completed the questionnaire independently (not counting when they worked together), there were differences in their expectations of stress and the number of calls to their provider about finances. Twice as many consumers than informal carers disagreed that self-managing would be more stressful (71% vs. 32%, respectively). Almost all consumers (97%) expected self-managing to lead to fewer calls to their provider about finances compared to 70% of informal carers (see Table 3).

Informal carers had significantly higher expectations that self-managing would result in more stress (Mdn = 4) than consumers (Mdn = 2) ($U = 372.0$, $p < .001$, $r = .44$). Notably, a median of 4 suggests that their expectations were only moderate. Consumers (Mdn = 6) reported significantly higher expectations than informal carers (Mdn = 5) that they would make fewer calls to their provider regarding finance and budget issues ($U = 489.5$, $p = .004$, $r = .32$), and that they would have a more positive relationship with their provider (Mdn = 6) than informal carers (Mdn = 5) ($U = 546.0$, $p = .021$, $r = .26$).

[Insert Tables 4 & 5 about here]

Consistent with the optimistic findings summarised in Table 3, most participants considered themselves unlikely to experience any of the specific risks presented (see Table 4). Informal carers had higher expectations of risk when self-managing than consumers, particularly having poorer outcomes through not knowing the system well (24% vs. 3%, respectively), and running out of money (16% vs. 0%, respectively) (Table 4). The telephone interviews reinforced this finding. These differences were examined with a series of Mann-Whitney tests and statistically significant differences were found for all items (Table 5).

[Insert Table 6 about here]

Table 6 shows the frequency of topics discussed in interviews. The need for information was most frequently mentioned; followed by dissatisfaction with previous providers; expecting

to save on administration costs; to have more choice and control and flexibility when using funds; and being able to select support staff.

Nine of the 18 consumers interviewed were self-managing elements of their home care package prior to the trial. This unexpected finding and subsequent discussions with providers revealed there was a spectrum of experience amongst providers and a range of self-management models. Some had years of experience supporting consumers to self-manage while others were taking their first steps. All hoped to improve their ability to provide self-management by joining the trial.

The themes from interviews and open-ended questionnaire responses provide contextual insights into why participants wanted to self-manage, their expectations and attitudes to risk. One quote succinctly summarised the views of many:

> The [previous] provider I have been using has caused me undue stress over the last 18 months. I believe that I would have more control of the time I require support workers and I would also not have the administration costs that are presently imposed [if I self-manage]. I would work with support workers who understand my needs and are very professional and yet very caring and gentle. I am looking forward to the [debit] card which I expect will make payments easier. I would like to think my current service provider will provide relevant information to support a smooth transition to self-managing, i.e. work with me during the transition period.
> (Consumer 1, no prior self-managing experience, online questionnaire completed independently)

This comment shows: i) dissatisfaction with a previous provider where support workers had inflexible rosters and were unavailable when needed; ii) hopes to pay reduced administration costs; iii) a wish to select support workers; iv) interest in using the debit card to pay for goods and services; v) a need for more information; and vi) an expectation that the provider will support self-managing, especially during the transition period.

A second respondent added:

> I really struggled with a previous provider, … staff worked to a roster and I didn't know when they were coming, and sometimes they didn't show up. … I'd get different people all the time… There were varying degrees of competency, it was quite stressful.
> (Daughter of Consumer 2, currently self-managing, telephone interview)

A third respondent said:

> Staff [at my previous provider] were patronising and controlling. I felt disempowered, oppressed and suffocated… They didn't tell me what money was available. It's important for my mental health to have control over my life. The legislation backs me up, but it didn't happen with first provider.
> (Consumer 3, CALD, currently self-managing, telephone interview)

While most respondents were optimistic that self-managing would alleviate problems, some were wary. One said:

> I have little idea what self-managing really means. I want clear information about the rules and what can be purchased, I need to know the mechanics of self-managing.
> (Consumer 4, First Nation, no prior self-managing experience, interview).

Participant's greatest concern, expressed in open-ended comments on the questionnaire, was not knowing how to effectively navigate the aged care system (see Table 6). Most were confident that they had the skills and abilities to manage adequately if given enough information and support, with many referring to their professional competence. Typical comments were:

> In my working life, I was in finance and accounting, preparing budgets, hiring staff and researching material etc….my disabilities have had an enormous effect on my health, wellbeing and mobility but I am still able to

manage my finances.
(Consumer 5, no prior self-managing experience, online questionnaire completed independently)

I am an approved nurse and I am assisting my parents with self-managing their package. I am intimately aware of their needs and understand the aged care system. I am also a bookkeeper so understand balancing budgets and sticking within a budget.
(Daughter of Consumer 6, currently self-managing, online questionnaire completed with informal carer)

Some participants held concerns for others but not for themselves, for example:

[There are risks] in general, but not for me specifically, I think there are more risks associated with appropriate spend, misuse of funds intentionally or inadvertently … compared to an agency managed package … I think there can be increased stress when managing conflict or under performance issues [with staff], but less stress in terms of feeling in control compared to a fully managed package.
(Spouse of Consumer 7, currently self-managing, online questionnaire completed with informal carer)

There was a strong expectation that service providers would offer transition and ongoing support. A typical comment was:

I would like user friendly tools and clear information, also a 'go to person' if I get stuck and need answers, and enough time to get my head around the information and learn how to use the technology. I currently use internet banking as part of home admin.
(Consumer 8, no prior self-managing experience, online questionnaire completed independently)

The interviews indicated that the participants' main concern was not being adequately prepared and resourced to make full use of the self-managing options.

Participants considered their education and professional skills to be protective factors against risks.

Discussion

The data show that most participants chose to self-manage because they expected to have more control organising services, more funds to spend and better outcomes compared to agency managed services. While many, but not all participants expressed dissatisfaction with their prior services, they perceived great merit in the trial model. Their positive expections of self-managing mirrored those found in a previous CDC study by Kaambwa et al. (2015) where participants hoped to save unused package funds, use these flexibly, and select their support workers.

Participants' motivations and expectations align with the four personal components of Hur's empowerment theory (2006): meaning, competence, self-determination and impact. Hur defines meaning as having a fit between one's actions, values, beliefs and behaviour and argues that these concepts are interdependent. Participants voluntarily chose to participate because they were giving meaning to their lives by taking control of their aged care package and organising services to support their lifestyle. Additionally, they gained meaning through contributing to the body of evidence regarding self-management of home aged care. They needed information to achieve this, which was the most frequently discussed topic in interviews. They expected lower administration costs and more money to spend on services and supports, the opportunity to use package funds more flexibly and to select support staff. Hur's empowerment theory proposes that the wider context impacts on individuals, especially when they have low agency and autonomy, such as home aged care service consumers. This was demonstrated when negative staff attitudes impacted on CDC consumers in other studies (Orpin et al., 2016; You, Dent & Doyle, 2017; Payne & Fisher, 2019). This indicates that supportive and positive staff are needed to achieve successful outcomes in the forthcoming self-managing trial.

The findings in this study give no comfort to coordinators and support staff who were concerned that consumers will treat them like employees (Payne & Fisher, 2019).

Consumers joined the trial to avoid staff making decisions for them. They wanted more control and planned to recruit support workers who would be directly accountable to them as their employer. It will be interesting to see how support workers feel about this arrangement.

Interestingly, the negative attitudes of consumers towards CDC found in some other studies (Day et al., 2018; Gill, Bradley, Cameron, & Ratcliffe, 2018; KPMG, 2015), were not found in this study. This difference may have resulted because CDC was being imposed in the previous studies, whereas participation in this trial was voluntary. Table 3 shows participants had overwhelmingly positive expectations, and were confident of their ability to self-manage as long as their provider offered information and support.

Many participants had higher than average education levels (Australian Bureau of Statistics, 2012), which may have contributed to their optimism, confidence and sense of empowerment. The requirement to have online access possibly skewed the sample towards people in higher socio-economic levels who had higher education, although all education levels were represented. No mention of education levels was made in previous studies. The trial purposefully invited consumers from diverse communities to test self-management, as recommended by Manthorpe and Samsi (2013). We know that CALD consumers have difficulties accessing services (Department of Health, 2017), and CALD consumers were underrepresented in this trial. It is anticipated that the post-trial mixed-methods analysis will show whether the resources developed prove adequate to support diverse populations to self-manage.

The consumer's age, health and mental capacity were not a barrier to participating in the trial if informal carers were available to undertake administrative responsibilities. Questionnaire and interview answers indicated that informal carers will be the primary 'managers' and 'decision makers' for most consumers in the trial, although the interviews included people in this age group who planned to manage independently. An important finding in this study was that consumers who completed the questionnaire independently reported statistically significantly different perceptions of stress and risk compared to their informal carers, who were supposed to represent their views. Other studies have found a

significant difference when examining proxy reports from carers of older people (Moyle et al., 2012). These findings raise ethical and practical issues about how to ensure the consumer's voice is heard and warrants further investigation in in future studies.

Participants wanted more information, an issue that is widely recognised in international and Australian self-managing program evaluations (McGuigan, McDermott, Magowan, McCorkell, Witherow & Coates, 2015; Laragy, David, & Moran, 2016). This study reinforces the need for information about financial and administrative processes, rules and regulations, responsibilities, services and support options. Information needs to be provided in timely and culturally appropriate ways, especially for 'hard to reach' groups. These requirements are easier to list than to deliver as all programs cited above found it challenging delivering the necessary information.

The data show that concerns about possible risks were minimal, with informal carers expressing more concerns than consumers. The Australian and international self-managing studies discussed above found no increase in adverse incidents, and many programs have policies and procedures in place to safeguard against possible fraud, emotional, physical and financial abuse (Littlechild, Glasby, Niblett, & Cooper, 2011; Sciegaj et al., 2016). The Royal Commission into Aged Care's findings of widespread abuse place a responsibility on self-managing programs to ensure safety. The challenge is to do this without stifling autonomy.

The limitations of this study were: the trial sample was small and not representative and required participants to be computer literate and have internet access; the interview questions and questionnaire were piloted with representatives on the project Steering Committee and not a wider sample. Taking notes rather than recording and transcribing interviews potentially resulted in some oversights. To minimise this possibility, the interviewers reiterated key experiences and perceptions at the end of each interview and notes were typed immediately after interviews. This is a process of improving trustworthiness of analysis through member checking (Fossey, Harvey, McDermott, & Davidson, 2002). There was consistency in reports across participants and data saturation was achieved. To minimise response biases, including 'demand characteristics' bias, participants were assured of confidentiality and the independence of the researchers from

COTA Australia. The findings cannot be generalised to other self-managing programs because of these limitations and because there is no standardised self-management model. These limitations could be addressed in further studies of self-managed home care packages.

In conclusion, this study informs the aged care sector of dissatisfactions with agency-managed services and consumers' wishes to be empowered by having greater choice and control. Participants were confident in their ability to self-manage and had minimal concerns about possible risks. Service providers are alerted to the possibility of abuse and neglect by the Royal Commission's findings and they retain responsibility for consumers' wellbeing. Consequently, service providers face challenges managing risks while facilitating empowerment, independence and agency in older people, as is their right.

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Consumer expectations of self-managing aged home care packages in Australia

Table 1.

Demographic characteristics of all participants, and surveys completed by consumers independently, completed with an informal carer, and completed by an informal carer on behalf of the consumer (n = 99).

		Consumer completed survey independently (n = 32)		Consumer completed survey with informal carer (n = 17)		Informal carer completed survey on behalf of consumer (n = 50)		Total sample (n = 99)	
		n	%	n	%	n	%	n	%
Gender	Female	24	75%	11	65%	33	66%	68	69%
	Male	8	25%	5	29%	17	34%	30	30%
	Gender diverse	0	0%	0	0%	1	2%	1	1%
Age group	Under 39 years	0	0%	0	0%	1	2%	1	1%
	40 – 49 years	0	0%	0	0%	0	0%	0	0%
	50 – 59 years	2	6%	0	0%	0	0%	2	2%
	60 – 69 years	7	22%	3	18%	4	8%	14	14%
	70 – 79 years	12	38%	5	29%	15	30%	32	32%
	80 – 89 years	10	31%	9	53%	18	36%	37	37%
	90 years and over	1	3%	0	0%	12	24%	13	13%
Cultural identity^	ATSI†	3	75%	1	25%	0	0%	4	4%
	CALD‡	3	27%	2	18%	6	55%	11	11%
	Military veteran	0	0%	0	0%	3	100%	3	3%

	LGBTIQ+	0	0%	0	0%	0	0%	0	0%
Package level	Level 1	1	3%	0	0%	3	6%	4	4%
1=lowest	Level 2	16	50%	8	47%	16	32%	40	40%
	Level 3	5	16%	4	24%	7	14%	16	16%
	Level 4	10	31%	5	29%	24	48%	39	39%
Highest education	Years 7-9	3	9%	1	6%	1	2%	5	5%
level	Years 10-12	7	22%	2	12%	6	12%	15	15%
	Trade	3	9%	3	18%	12	24%	18	18%
	University	19	59%	11	65%	31	62%	61	62%

^n is expressed as a percentage of participants who identified with each cultural identity because this question offered a multiple responses.

†"Aboriginal or Torres Strait Islander".

‡"Culturally and Linguistically Diverse".

Table 2.

Highest level of education completed by participants compared with Census data of older people aged 65 years and over (n = 99).

Highest level of education completed	Sample		% in Australians aged 65 years and over †
	n	%	
Years 7-9	5	5%	approx. 22%^
Years 10-12	15	16%	61%
Trade	18	19%	10%
University	61	60%	4%
Total	99	100%	97%

†Australian Bureau of Statics, ABS. 2012 Census

^High school achievement between Year 7 and 9 was not specifically reported. Approximately 2.4% of older people reported that they had never attended school.

Table 3.

Expectations of self-managing home care packages, as answered by consumers independently, consumers with an informal carer, or by informal carers on behalf of the consumer, and all participants (n = 97).

		Consumer completed survey independently (n = 31)		Consumer completed survey with informal carer (n = 16)		Informal carer completed survey on behalf of consumer (n = 50)		Total sample (n = 97)	
		n	%	n	%	n	%	n	%
More money to spend on services and supports	Agree	23	74%	16	100%	38	76%	77	79%
	Neutral	5	16%	0	0%	8	16%	13	13%
	Disagree	3	10%	0	0%	4	8%	7	7%
Positive changes in my relationship with my provider	Agree	22	71%	13	81%	29	58%	64	66%
	Neutral	7	23%	3	19%	19	38%	29	30%
	Disagree	2	7%	0	0%	2	4%	4	4%
Positive changes in my relationship with my informal carer/ family	Agree	18	58%	12	75%	28	56%	58	60%
	Neutral	9	29%	4	25%	20	40%	33	34%
	Disagree	4	13%	0	0%	2	4%	6	6%
Positive changes in relationship with paid support workers	Agree	24	77%	12	75%	28	56%	64	66%
	Neutral	5	16%	3	19%	18	36%	26	27%
	Disagree	2	7%	1	6%	4	8%	7	7%

Fewer calls to my provider regarding finances	Agree	30	97%	14	88%	35	70%	79	81%
	Neutral	1	3%	2	13%	13	26%	16	16%
	Disagree	0	0%	0	0%	2	4%	2	2%
More stress	Agree	2	7%	4	25%	18	36%	24	25%
	Neutral	7	23%	4	25%	16	32%	27	28%
	Disagree	22	71%	8	50%	16	32%	46	47%
More risk	Agree	6	19%	2	13%	14	28%	22	23%
	Neutral	8	26%	4	25%	17	34%	29	30%
	Disagree	17	55%	10	63%	19	38%	46	47%

Table 4.

Consumer perceptions of risk when self-managing home care packages, as answered by consumers independently, consumers with an informal carer, or by informal carers on behalf of the consumer, and all participants (n = 96).

		Consumer completed survey independently (n = 31)		Consumer completed survey with informal carer (n = 16)		Informal carer completed survey on behalf of consumer (n = 49)		Total sample (n = 96)	
		n	%	n	%	n	%	n	%
I might run out of money and leave myself short	Likely	0	0%	0	0%	8	16%	8	8%
	Neutral	3	10%	1	6%	6	12%	10	10%
	Unlikely	28	90%	15	94%	35	71%	78	81%
I might make mistakes and spend my funds inappropriately	Likely	1	3%	1	6%	3	6%	5	5%
	Neutral	1	3%	0	0%	7	14%	8	8%
	Unlikely	29	94%	15	94%	39	80%	83	86%
I might compromise my clinical care needs because I have less case manager oversight	Likely	1	3%	0	0%	6	12%	7	7%
	Neutral	1	3%	0	0%	6	12%	7	7%
	Unlikely	29	94%	16	100%	36	73%	81	85%
	Likely	1	3%	0	0%	5	10%	6	6%
	Neutral	1	3%	1	6%	6	12%	8	8%

I might employ unsuitable/unqualified care staff who are unable to meet my needs	Unlikely	29	94%	15	94%	38	78%	82	85%
I might have difficulty setting goals for myself to develop my care plan	Likely	0	0%	1	6%	6	12%	7	7%
	Neutral	3	10%	0	0%	10	20%	13	14%
	Unlikely	28	90%	15	94%	33	67%	76	79%
I might have poorer outcomes because I don't know how to navigate the aged care system	Likely	1	3%	2	13%	12	24%	15	16%
	Neutral	4	13%	2	13%	11	22%	17	18%
	Unlikely	26	84%	12	75%	26	53%	64	67%

Table 5

Perceived risk when self-managing home care packages: medians and Mann-Whitney test results of differences between consumers independently and informal carers on behalf of consumers (n = 80).

	Median		Mann-Whitney U	p-value	r
	Consumer completed survey independently (n = 31)	Informal carer completed survey on behalf of consumer (n = 49)			
I might run out of money and leave myself short	1	2	537.5	.018	.26
I might make mistakes and spend my funds inappropriately	1	2	482.5	.003	.33
I might compromise my clinical care needs because I have less case manager oversight	1	2	528.0	.016	.27
I might employ unsuitable/unqualified care staff who are unable to meet my needs	1	2	528.5	.012	.28
I might have difficulty setting goals for myself to develop my care plan	1	2	406.5	.000	.42
I might have poorer outcomes because I don't know how to navigate the aged care system	1	2	492.0	.006	.31

Table 6.

Frequency of themes that arose during telephone interviews (n = 18)

Themes	Frequency across interviews
More information about self-management in the trial	15
Dissatisfaction with previous provider or arrangements	14
Save on administration costs	12
Flexible use of funds	11
More choice and control over services and supports	11
Select support staff	11
Access account balance in real time	5
Help others by sharing information about self-management	5