

Decision-making in home care package spending

Diane Rowland¹ | Catherine M. Joyce^{1,2} 

¹Benetas, Melbourne, Vic, Australia

²School of Public Health and Preventive Medicine, Monash University, Melbourne, Vic, Australia

Correspondence

Catherine M. Joyce, School of Public Health and Preventive Medicine, Monash University, Melbourne, Vic, Australia.
Email: Catherine.Joyce@benetas.com.au

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Abstract

Objective: To understand the motivations and drivers of spending decisions made by home care package recipients, in the context of high levels of unspent funds.

Methods: Qualitative study using 30 semi-structured interviews with 38 home care package clients and/or client representatives in rural and urban Victoria conducted between December 2018 and March 2019. Interview transcripts were analysed to determine themes.

Results: Spending decisions were influenced by assessment and entry experiences, knowledge and understanding of package funds, availability and acceptability of services, and attitudes to spending.

Conclusion: Clients need confidence in their individual funds and their use in order to maximise the potential benefits. Clear, consistent communication at all stages, and additional supports to build consumer capability, will enable clients to better understand packages and their application. This in turn will optimise the capacity of home care package recipients to maximise their health and well-being.

KEYWORDS

aged, consumer behaviour, home care services

1 | INTRODUCTION

The Australian Government Home Care Package program is intended to provide choice for consumers with regard to type of services, how and when services are delivered and by whom, as well as control over package funds.¹ In 2017, it was estimated that almost half (47.3%) of packages had unspent funds, totalling up to \$350 million.² By the end of 2019, it is estimated that there will be an average of \$7000 unspent funds per client, totalling approximately \$600 million.³ The Australian Government Department of Health identifies several possible contributing factors to this, specifically: clients choosing periods of temporary leave; clients holding contingency funds; and automatic package upgrades.⁴ The Department emphasises the need for providers to reduce unspent funds wherever possible. However, it is currently

unclear as to whether the accumulation of funds is planned or unplanned by clients, and the role of underspending vs over-allocation. There is little published research into this area, with none focussing specifically on clients' perceptions or behaviours, and no indication of what level of underspend is considered acceptable.⁵

In the early stages of consumer-directed care in Australian home care, there was limited knowledge and understanding of entitlements and options, and limited exercise of choice.⁶ Communication about packages, and budgets in particular, was reported as insufficient to support effective decision-making.⁷ The Australian Government's MyAgedCare website is designed to be a key source of information about government-funded aged care service.⁸ It provides information about available services (including costs), and assessment and referral processes to access services.⁸

[Correction added on 28th August 2020, after first online publication: The copyright line has been amended accordingly.]

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This research aimed to understand the motivations and drivers of home care package recipients' spending decisions. It aimed to explore a range of potential factors from client choice to system issues from the perspective of package clients.

2 | METHODS

This qualitative study focussed on home care package recipients from a single not-for-profit aged care provider in Victoria, Australia. A qualitative method was selected as the most appropriate to the study's aim of exploring individuals' experiences and motivations.⁹ Thematic analysis, in which themes found within the data are identified and analysed, was used in line with the exploratory nature of the study.¹⁰ Ethics approval was obtained from Monash University Human Research Ethics Committee (Project number 17580). Victoria has a population of 6.46 million, of which 4.96 million (76.8%) reside in the capital city, Melbourne, and the remainder in regional and rural areas.¹¹ One quarter (25.9%) of Victoria's population were born overseas, and 15.3% are aged 65 years or more.¹¹ There are over 30 000 people on home care package in Victoria, with one of 333 approved home care providers.¹²

Maximum variation sampling was used with an aim of including a heterogeneous group of home care clients, across geographical regions, packages levels and whether currently underspending or not. Because the potential pool of participants was large (approximately 900), sampling was implemented by randomly selecting clients to be approached to take part in the study, within defined strata. The total number of clients receiving packages from the provider was stratified by region, package level and degree of underspend. Region was defined as 'urban' or 'rural', using the existing regional structure of the provider, in which 'urban' includes greater Melbourne and 'rural' is the remainder of Victoria. Package level was defined by two groups: Levels 1 and 2 combined; and Levels 3 and 4 combined. Degree of underspend was defined as either 'underspent' or 'on target'. Underspent was defined as having a package balance greater than the value of 2-week emergency care, specific to each package level. Participants were excluded from the study if they had recently upgraded to a higher level package with services not yet activated. Across these strata, 73 clients were randomly selected to be invited to take part in the study.

Selected clients, or their known representative in the case of joint or substitute decision-makers, were contacted by regional home care staff by telephone or face-to-face to introduce the research, with potential participants who verbally consented then contacted by a researcher [DR]. Once data saturation was reached, no more potential participants were contacted. The female researcher, with a postgraduate diploma in health promotion, and extensive experience in conducting qualitative interviews, visited potential

Policy Impact Statement

The home care package market remains immature, and there are inherent uncertainties in managing expenditure appropriately over time in the context of changing needs. There is an opportunity to improve decision-making by enhancing information and navigation supports, and ensuring these are tailored to client needs and preferences.

Practice Impact Statement

This study confirms that home care package providers should ensure clear, consistent communication with consumers about clients' entitlements, clients' package balances and organisational systems for purchasing, reimbursement and planning. This will support more active engagement of clients in package management.

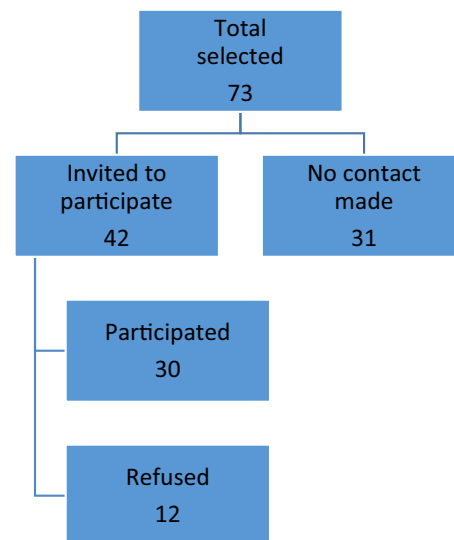


FIGURE 1 Sample recruitment. Note: 'No contact made': No invitation to participate was extended to this group as saturation was reached following completion of 30 interviews

participants to further explain the research, offer an opportunity to ask questions, and gain informed consent.

In total, decision-makers for 30 packages participated in face-to-face, semi-structured interviews (see Figure 1). Interviews lasted approximately 40 minutes and were conducted face to face by one researcher [DR], who was not previously known to the clients, in the client's home. Interviews were conducted between December 2018 and March 2019.

Interviews explored each recipient's entry into the package system, the assessment process, provider choice, and their knowledge and understanding of the package. Interviews were

TABLE 1 Sample characteristics

	Number
<i>Package characteristics</i>	
Number of packages	30
Package level	
Levels 1 and 2	17
Underspent	15
On target	2
Levels 3 and 4	13
Underspent	11
On target	2
<i>Geographical area</i>	
Urban	19
Rural	11
<i>Interviewee characteristics</i>	
Number of interviewees	38
Interviewee roles	
Client (C) only	14
Client and client representative (CR)	8
Client representative only	8
Client gender	
Male	5
Female	18
Client Representative gender	
Male	4
Female	11

audio-recorded and transcribed, using secure, encrypted file transfer procedures, by a third party transcription service (www.Rev.com). Interview transcripts were returned to participants to verify and were then de-identified and entered into N-Vivo 11 for analysis. One researcher [DR] undertook the analysis, using an inductive content analysis method. Following familiarisation with the data, initial codes were generated and themes identified. There was an iterative process, with the interview schedule continually developed from the themes emerging from the data, until data saturation was obtained. No repeat interviews were conducted. Themes were reviewed and agreed by both researchers.

On completion of analysis, all data were archived in de-identified format, with audio-recordings destroyed. On conclusion of the study, participants were provided with a summary of key findings in a de-identified format and invited to give feedback on the findings.

3 | RESULTS

A total of 38 clients and client representatives participated in 30 interviews (Table 1).

3.1 | Entry and assessment process

The initial pathway to receiving a home care package was varied. Several interviewees had been referred and assessed on hospitalisation (n = 12). This subgroup was unable to recall any specific application process, and many did not recall the assessment. Of those who could recall the process, none recalled 'waiting' for funds, and some appeared bewildered to find themselves receiving funding at all:

It just sort of happened and appeared. I don't even know how much it is, just telling the truth.

(Client Representative (CR) 5, Level (L) 1&2, urban, underspend)

I've got no understanding of who puts [money] in and why it's there.

(Client(C) 15, L3&4, rural, underspend)

Other pathways included GP referral (n = 4), applying directly through the MyAgedCare website (n = 3), council (n = 3) or other organisations (n = 3). Of the three recipients who applied directly, two had family members who had applied on their behalf, and one had applied themselves, on recommendation from hospital, though had not found the process easy.

The majority of those who could recall the assessment process had found it a positive and thorough experience, but there were concerns from some that they had 'misrepresented' themselves and had forecasted their future needs incorrectly:

We talked up our capabilities. You don't accept that it's going to deteriorate. You expect that it's going to improve.

(CR7, L1&2, rural, underspend)

A number of interviewees reported carefully considering which provider to choose, with the main reasons cited including initial communication and reputation:

It was a 2 way communication and I was impressed by that.

(CR2, L3&4, rural, underspend)

We got more feeling of trust and stability from [the provider].

(C14, L1&2, rural, underspend)

My dad (client) picked [the provider]. He just clicked with [staff name].

(CR16, L3&4, urban, underspend)

Many did not perceive there to have been a choice:

That's the provider the council was using at the time.

(CR5, L1&2, urban, underspend)

I was told [by the hospital] that there's so many people waiting for a package that it would be wise to take the first one that comes your way.

(C17, L1&2, urban, underspend)

[The case worker] happened to turn up...She just turned up, and I knew nothing about it.

(C9, L3&4, urban, underspend)

I didn't look for anyone else because I couldn't be bothered.

(C8, L1&2, rural, underspend)

3.2 | Knowledge and understanding of the package funds

Many recipients were not confident of their package level:

Wonder what package I'm on. I think I'm on (level) one.

(C1, L1&2, urban, underspend)

I don't know whether my case manager didn't tell me when my level increased.

(C3, L3&4, urban, underspend).

Communication issues hampered the ability to understand for some, ranging from non-English as the primary language to hard of hearing:

I don't make much arrangement over the phone. First of all, because of my poor hearing....I just can't follow them.

(C2, L1&2, urban, underspend)

Clients were aware of receiving monthly statements from the provider, but did not necessarily know or have confidence in the amount of funds available. Reasons included misinterpreting credits for debits, not understanding the terminology used and not understanding payments for retrospective and reimbursed services:

I don't really understand written figures.

(C15, L3&4, rural, underspend)

I don't understand the jargon.

(C2, L1&2, urban, underspend)

I don't know what they took out of it or not.

(C6, L1&2, urban, underspend)

There were five clients who were required to financially contribute to the package funds. In two of these, the client contribution had been miscalculated and there were ongoing issues regarding the amount, though both had been supported by the provider:

The government letter was quite confusing and it said [the contribution] was a lot more than that, which I said was absolute rubbish.

(C15, L3&4, rural, underspend)

Some interviewees had received unexpectedly high charges for those services, which were subcontracted, adding to their confusion over the costs:

the district nurse...told me to contact the council...but then we started getting the bills.

(C16, L1&2, rural, underspend)

This was also the case for recipients who had pre-existing relationships with carers, cleaners or tradespeople through former funding, and had wanted to retain their services through package funds:

We were paying \$4.20 to the council for them to come to watch (sister). And because the care was so good, we said "oh we'll keep her on." And from \$4.20 they charged \$77.

(C17, L1&2, urban, underspend)

Many participants did not understand the fees charged by the provider, and felt there was a lack of transparency about fees. In combination with uncertainty over package levels, contributions and fees, there was a sense of overall confusion about the amount available to spend, and the general purpose of the package:

I don't know what she's entitled to.

(CR16, L3&4, urban, underspend)

I don't know how anybody could possibly spend it 'cause I don't know how much goes in every month'.

(C15, L3&4, rural, underspend)

I just don't really ask for anything, it never occurred to me.

(C11, L1&2, urban, underspend)

Well it's mainly a cleaning package but recently they told me what I'm entitled to because my money was accumulating.

(C17, L1&2, urban, underspend)

No participant recalled being informed by either the assessor or the provider about temporarily suspending the package if they take leave. In general, interviewees did not see an opportunity to temporarily pause the funds. Many services provided to lower package holders were specific to gardening and cleaning that would potentially continue even if the client was away from home. For those with greater care needs, there was no prospect of excursions:

Where would I go? I don't go on holiday. I don't go anywhere. I can't.

(CR4, L3&4, urban, underspend)

The opportunities for recipients to gain extra understanding of the package system appeared to be limited to the MyAgedCare website and/or the provider (usually the case worker). Only five recipients were aware MyAgedCare, and of those accessing it, there were concerns expressed in navigating:

You've got to get through so much bloody rubbish to get to the bit you want.

(C15, L3&4, rural, underspend)

3.3 | Attitudes to spending

Participants' attitudes to spending varied immensely. Some were happy to spend:

I don't want any leftovers.... I've paid taxes all my life.

(C20, L3&4, urban, underspend)

Others felt it was unnecessary to spend the money:

If I don't spend it, it will go back to somebody that needs it so that's fine.

(CR14, L1&2, urban, underspend)

We're not using near the amount of money that's there, I know, but we really don't need it.

(CR6, L1&2, rural, underspend)

I'm not one for having stuff for the sake of it. They come to say "would you like a new bed? No I don't want a new bed. Not for the sake of it, no.

(C4, L3&4, rural, underspend)

For those clients who were required to financially contribute to the package funds, there was an awareness of spending not just government money but their own:

We're still paying some, so I don't want to waste it as such, if that makes sense.

(CR12, L3&4, urban, underspend)

There were many who were conscious of the need to have a reserve of funds as a contingency, though some believed this to be an official requirement:

I thought that was part of the rules and regulation[s]—that you had to have about 20% as a safety net or something.

(CR1, L3&4, rural, underspend)

Many interviewees chose to set funds aside, for specific events or equipment:

I've been trying to save it up for the school holidays. So when my kids are at home I have the extra care for my mum during the holidays.

(CR12, L3&4, urban, underspend)

Some were choosing to use it as an emergency care if their situation deteriorated and their care needs increased:

Down the track there'll be something I need. Well I know then that I've got money there.

(C6, L1&2, rural, underspend)

I consider that just an emergency fund in case things go wrong.

(CR5, L1&2, urban, underspend)

I've got heaps. But I want to because if I start having personal care, I'm going to eat into it.

(C1, L1&2, urban, underspend)

In two interviews, where both client and client representative were package holders, spending decisions were influenced by the combined level of resourcing:

I think the time I had a little bit of concern was if [partner—Level 4 client] passed away and how would I cope with just a level 1.

(CR8, L3&4, rural, underspend)

I've [been unwell] It's just a bit much for me at the moment...it wouldn't be worth (getting extra help)...they said you've got enough coverage with (wife's) package.

(CR5, L1&2, urban, underspend)

Often there was no conscious decision to save funds:

I've been in hospital that much, that it's built up that much, ...which is good because if I'm sick, that's a carer and I'm happy with that.

(C21, L3&4, urban, underspend)

There's not a plan.

(CR1, L3&4, rural, on target)

There were some inconsistencies across regions as to what was regarded as permissible to purchase from funds, with case workers interpreting guidelines differently:

Well I've got a very nice washing machine... because it conked out.

(C4, L3&4, rural, on target)

I was a bit surprised that they wouldn't pay for [washing machine] ...it's absolutely crucial.

(CR2, L3&4, rural, underspend)

Adding to this confusion was the fact that there were few clear messages from allied service providers and health professionals regarding what could be paid for by the package—recipients were not asked if they were package holders prior to paying for external services and commodities:

We didn't know we could have dental.

(C4, L3&4, rural, on target)

Do they cover shoes? I don't know.

(CR6, L1&2, rural, underspend)

For some recipients, previous negative experiences and worries about refusals prevented them from making further requests:

It felt like the door had closed on [me] head.

(CR9, L3&4, rural, underspend)

Sometimes because of our ages, we feel guilty asking for something. Especially something I would have thought I'd be able to have easily, but no.

(CR15, L3&4, urban, underspend)

It was not always clear to recipients how to utilise services that they had accepted, for example taxi cards:

I don't understand...Do I just ring up a taxi and say, "There's a taxi card" or do I go down and talk to the taxi driver and say, "Look, this is a taxi card, but I don't know what to do with it"?

(C8, L1&2, rural, underspend)

There was additional concerns over paying for items and services upfront and having these costs reimbursed:

I didn't know they could reimburse you—[case worker] used to say, well if you paid for it first we can't do that.

(C9, L3&4, urban, underspend)

This was sometimes preventing recipients from choosing to spend their funds on services which they stated they would like:

She's got to pay for [food] up front and then claim it, so that's worrying her, so that's why we've never done it.

(CR13, L1&2, urban, underspend)

Extra services could sometimes be perceived as extra hassle, particularly when participants had experienced past difficulties in service provision, leaving them reluctant to request more. In some (mostly rural) geographical areas, the required/desired services or equipment was simply unavailable:

It's hard 'cause here taxis are impossible, there's only 3 [available].

(C16, L1&2, rural, underspend)

I got in touch with the team leader who's lovely. And she said "Well we're doing our best. We are trying to get a builder. We can't get a builder at the moment".

(C4, L3&4, rural, on target)

Because [the client] can be difficult... I would like him to have a man come and look after him.
(CR15, L3&4, urban, underspend)

He's declined to [have female personal carers], it doesn't feel right to him.
(CR8, L3&4, rural, underspend)

Many stated that they would willingly use funds for respite and meal provision services:

I believe that there's a lot of people who've got excess money and a package will not pay for their respite.
(CR1, L3&4, rural, on target)

I'm assuming that the cost of that would be funded out of the package, if it's residential respite.
(CR2, L3&4, rural, underspend)

For a minority, unspent funds made led to feeling anxious and not in control:

It makes me lose sleep—night after night I'll wake up, with a screwed knot inside.
(CR3, L3&4, urban, underspend)

For the majority of participants, however, package funds equated with security, across all package levels:

There's plenty of money. It's been very nice—a really good experience.
(CR4, L3&4, urban, underspend)

I know I can ring up and get a carer.
(C15, L3&4, rural, underspend)

...it's something I never had before.
(C5, L1&2, rural, underspend)

4 | DISCUSSION

In this study, home care package recipients' spending decisions were influenced by assessment and entry experiences, knowledge and understanding of package funds, availability and acceptability of services, and attitudes to spending. There were no clear differences between those with unspent funds, and those with 'on target' spending, although the latter group was very small.

The findings indicate that knowledge and understanding about entitlements, available funds and processes associated with home care packages continues to be low, 3 years after the introduction of consumer-directed care. The degree of engagement in active management of package funds was also relatively low. People's ability to make well-informed choices about their package spending was influenced by lack of information and lack of active engagement by assessment services at the outset, and by difficult-to-understand information about package balances over time, and lack of clarity about entitlements. These results are consistent with previous research.^{6,7,13}

Also impacting on people's ability to make optimal use of their package funds is an immature market, with gaps in desired services on the supply side as well as consumers lacking both information and confidence on the demand side. Consistent with this is recent research which indicates that people who have held packages for longer have an improved ability to manage package funds effectively.¹⁴

The evolving nature of current arrangements also serves as a reminder of the magnitude of the transition associated with the consumer-directed care model. The principles of choice and control underpinning the home care package model represent a significant philosophical change from the traditional, paternalistic culture of community aged care services.¹³ While services may traditionally have been person-centred in the sense of understanding individual needs and preferences, and in focusing on care relationships, they were not routinely rights-based, enabling meaningful engagement in decision-making.¹⁵ It would appear that providers may still be grappling with the shift in power entailed in the principles of choice and control, as evidenced by limited use of strategies to support people to actually exercise choice and control, such as ensuring information is clear and user-friendly, and genuine opportunities to tailor services.¹⁵ Indeed, international research suggests that clarifying exactly what people would like increased choice about and the impacts of this on outcomes such as quality of care and quality of life remain to be understood.¹⁶

The findings should be viewed in the context of the inherent challenges in spending the 'right' level of funds. Future health and care needs are inherently uncertain, and participants were attempting to forecast these as part of decision-making. Wait times for packages have increased substantially over time, averaging over 12 months for Levels 2-4.¹⁷ It is unsurprising therefore that clients feel the need for contingency funds as they worry about potentially escalating care costs for themselves, or their partner. In addition, a four-tiered funding model is always going to result in imperfect alignment between assessed need and funding provided. These inherent challenges, along with individual differences in attitudes to spending, mean that there will always be some level of underspending in the system.

The features of the home care market mirror those seen in the early stages of the National Disability Insurance Scheme, where approximately 31%-40% of committed funds were unspent, due to ineffective planning, insufficient supply of appropriate service, poor access to information about allocated funding and difficulties navigating the system.¹⁸

This study is based on a small sample of home care clients from a single not-for-profit provider, and as such may not be representative of the home care client population at large, and/or with other provider types. The study was not intended to provide a representative sample, but rather to identify the types of factors and issues that can impact on spending decisions. This study did not explore differences between clients making decisions about their own packages, compared to packages with joint or substitute decision-makers. Given existing research on systematic differences between care recipients and proxies with regard to perceptions of care quality and outcomes,^{19,20} this would be worth investigating in future research on home care package decision-making. The study did not explore other aspects of home care packages, such as use of subcontracted services, or self-managed vs case-managed (provider-managed) packages.

Future research could also usefully explore: the prevalence of the factors identified in this study with a larger, more diverse sample; the relationship between package spending decisions and use of third party (subcontracted) providers and with different package management arrangements; differences by characteristics such as age or level of functioning; and the impact of expenditure decision-making on care outcomes.

The implications of this research for providers include the need to ensure there is frequent, clear and appropriate communication, consistent across all clients. In particular, financial statements that are clear and user-friendly are a key element of supporting clients to make informed decisions.¹³ Also important are reliable and suitable services, and smooth, transparent processes for purchases, reimbursement and forward planning. These will enable recipients to have confidence in their budget and in utilising the funds in the most suitable manner for their needs and preferences.

This study has also highlighted the need for additional sources of advice and support to ensure that clients are empowered to make informed decisions. The assumption seems to be that clients will seek their own sources of information and advice to manage their packages. However, aged care literacy in the community continues to be low, with over 70% of older people never having looked at the MyAgedCare website.²¹ In this research, only three participants had looked at MyAgedCare. There are opportunities at the assessment stage to increase support, and ensure that clients and/or their representatives are actively engaged in the assessment process. This can help set people up to manage packages actively and effectively. The Aged Care System Navigator trials, which

are currently underway, may assist in filling the current gap in supports.²²

5 | CONCLUSIONS

Package funding gives security to many, but clients need confidence in their individual funds and their use in order to maximise the potential benefits. While attitudes to spending have some influence on package expenditure decisions, equally important is the context of a still-maturing home care market. Gaps remain in supports to empower clients to engage as active, informed consumers. Clear, consistent communication at all stages, and additional supports to build consumer capability, will enable clients to better understand packages and their application. This in turn will optimise the capacity of home care package recipients to maximise their health and well-being.

CONFLICTS OF INTEREST

The authors are employees of the organisation in which the study was carried out.

ETHICAL APPROVAL

Ethics approval was obtained from Monash University Human Research Ethics Committee (Project number 17580).

ORCID

Catherine M. Joyce  <https://orcid.org/0000-0001-6378-0743>

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