

# Consumer experiences of home care packages

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## Abstract

**Objective:** The study aimed to explore consumers' experiences of receiving a home care package (HCP).

**Methods:** Community engagement was used to recruit older people approved for a HCP. Data were collected through face-to-face interviews, and data analysis identified themes.

**Results:** Effective consumer-directed care depends on access to reliable information. Participants who reported satisfactory experiences had: (a) providers that charged reasonable fees; (b) case managers who delivered person-centred care; (c) support workers who were consistently assigned to them; (d) a family member for support and advocacy; and (e) ongoing community engagement.

**Conclusion:** Positive consumer experience requires tighter regulation of providers and policy attention to fees and minimal standards of staff training. The policy of full cost recovery restricts consumers' access to local government services.

## KEYWORDS

geriatrics, home care services, qualitative research, social isolation

## 1 | INTRODUCTION

Older Australians have indicated they prefer to remain in their own homes as they age.<sup>1</sup> The Commonwealth Home Support Programme (CHSP) and home care packages (HCPs) have been designed to delay the need for older people to move into an aged care home.

There are four levels of HCP, ranging from Home Care Level 1 (basic care) to Home Care Level 4 (high care). The Federal Government is the primary funder and regulator of the aged care system. The Aged Care Act 1997 and associated Aged Care Principles set out the legislative framework for the provision of HCPs.

HCP providers must apply to the Commonwealth Department of Health for approval to deliver services. Applicants are assessed against criteria stipulated in the Aged Care Act 1997. People receiving HCPs may also access services under the CHSP. Clients on HCP 1 and 2 are charged a subsidised rate for CHSP services (eg meals, transport, nursing, social activities). Clients on HCP 3 and 4 are charged on a full cost recovery basis.<sup>2</sup>

In June 2015, the Australian Government introduced the *Increasing Choice in Home Care* reforms. These reforms were designed to increase consumer choice and flexibility and to create a more competitive and innovative market for providers of home care.<sup>3</sup> Consumer-directed care aims to provide older people with greater control by allowing them to make informed choices about (a) the types of services they access and (b) the delivery of those services, including who will deliver the services and when they are delivered.<sup>4</sup>

Some use the term 'consumer-directed care' to describe a personalised approach to care; others to promote consumer choice in a market-based system.

Consumer-directed care has largely developed in the absence of evidence on the views and preferences of older people.<sup>5</sup> Day et al<sup>6</sup> explored recipients' experiences both leading up to the introduction of consumer-directed care and after its introduction.<sup>7</sup> Simons et al interviewed 45 older people to determine how well they understood the changes in home care.<sup>8</sup> The study found around 50 per cent were confused about the term 'consumer-directed care.' More recently, the Commonwealth Department of Health

commissioned AMR<sup>9</sup> and National Seniors<sup>10</sup> to conduct research among HCP clients and service providers. Both AMR and National Seniors reported recipients of HCPs were satisfied. However, consumers' experiences provide a more discriminating measure of a health service's quality and performance than questions about satisfaction.<sup>11-15</sup>

The aim of our study was to investigate consumer experiences of HCPs from a diverse range of perspectives. The Australian government commissioned the research. Detailed information about the project is provided in the published report.<sup>16</sup>

## 2 | METHODS

Recruitment strategies are described in the published report.<sup>16</sup> Information about the study was disseminated via social media. In addition, flyers were sent to home care providers. People who expressed an interest in participating in the research contacted the researcher. To be included in the study, participants must have been assessed for a HCP, irrespective of whether their HCP had been assigned.

Data were collected via face-to-face or phone interviews with the recipient. The interviews took place between 25 September and 20 November 2018. Interviews were approximately one hour in duration. Some participants chose to have a family member with them during the interview. Although questions were focused on the recipient of home care packages' experiences not the family members' experience, family members provided important data.

The interview schedule was semi-structured with open-ended questions. In some cases, all questions were asked. However, if participants became tired during the interview, only the key questions were asked (Table 1). With participants' permission, the interviews were tape-recorded. The data were analysed using thematic analysis.<sup>17,18</sup> The aim was to produce themes that were solidly grounded in the data.

This national research received approval from Peninsula Health HREC (HREC/18/PH/45).

**TABLE 1** Interview schedule: key questions

1. Tell me how you went about getting the services you needed.
2. Tell me about your experiences while you waited to receive your package.
3. How did you go about identifying and choosing your provider?
4. Tell me about your experiences with your chosen provider.
5. What is your understanding of the monthly statement/fees?
6. Tell me about your relationship with your case manager.
7. Are the services meeting your needs?
8. Tell me about staff who come to your home.
9. How has your quality of life changed since commencing your HCP?

### Policy Impact

The experiences of older people who receive home care packages highlight the importance of effective regulation of providers; clear, regulated fee structures; and mandatory staff training. The research findings also show how the policy of full cost recovery might be amended to improve access to local government services.

### Practice Impact

Feedback from recipients and family members may improve the way both providers and practitioners deliver home care packages. Recipients benefit from information about entitlements, clear financial statements, consistent staff assignment, and minimisation of administrative costs. The research findings also highlight the importance of assigning sufficient funds to social engagement.

## 3 | RESULTS

The sample comprised 37 participants (22 women and 15 men) from urban, regional and rural Australia. The average age was 82 years (range 66–95 years; median 83 years). The sample included older people who were socially isolated (N = 7), on low incomes (N = 5) and at risk of homelessness (N = 1); veterans (N = 1); Aboriginal and Torres Strait Islanders (N = 1); and older people who are culturally and linguistically diverse (N = 4) and from Lesbian Gay Bisexual Transgender Queer or Intersex communities (N = 2).

Table 2 describes the level of HCP that had been approved and assigned at the time of interview.

When asked to describe the best thing about in-home care, most participants replied as follows: '*It enables me to live at home.*' Without the government subsidy, participants said they would be unable to remain in their own homes.

The analysis of the data identified factors that are important to older people who receive a HCP (Table 3). These factors are discussed under the following themes: (a) access to reliable information; (b) providers; (c) reasonable fees; (d) case management; (e) support workers; (f) person-centred care; and (g) social engagement. These are expanded on below, with quotes from participants (in italics) as examples of responses. The published report provides a more comprehensive list of the themes that emerged from this research.<sup>16</sup>

**TABLE 2** Participants' age and details about their home care package/Community Home Support Programme

Participant Number	Age (years)	Approved	Assigned
1	81	4	4
2	81	2	CHSP
3	75	4	4
4	72	4	3
5	83	2	2
6	94	4	2
7	85	3	CHSP
8	91	3	3
9	67	4	4
10	75	2	2
11	83	4	4
12	90	3	3
13	88	4	4
14	68	4	4
15	87	4	4
16	72	4	4
17	88	2	2
18	88	4	4
19	95	3	3
20	69	4	4
21	79	4	2
22	74	4	4
23	86	4	No package
24	92	4	4
25	89	4	2
26	81	3	2
27	70	4	4
28	85	4	4
29	85	4	4
30	77	3	2
31	82	2	No package
32	86	4	3
33	90	2	2
34	66	2	2
35	92	2	2
36	85	4	4
37	83	2	2

### 3.1 | Access to reliable information

Participants welcomed the information in the fact sheets and brochures they had received. However, those who had additional questions said it was difficult to obtain reliable information from the My Aged Care information phone line/web page. Lack of access to accurate information made it difficult for them to make informed decisions.

*I would be transferred from My Aged Care to department to [another] department and then back to My Aged Care. I would spend five hours on the phone trying to find answers to my questions. It was like stepping onto a merry-go-round.*

*(Daughter of 90 year-old on a Level 2 HCP)*

Participants described the Home Care Agreement as 'too long and complicated.' Some participants signed the Home Care Agreement without understanding what they were signing. Participants also required ongoing information about types of services and entitlements that might be required as their circumstances changed.

*People are not being given guidelines that tell you what you can and can't have from your home care package.*

*(Daughter of 75 year-old on a Level 4 HCP)*

### 3.2 | Providers

Participants described a 'good provider' as one that delivered a high-quality, consumer-directed service and charged reasonable fees and fair hourly rates for support workers. However, providers did not always deliver genuine consumer-directed care.

*It was not consumer-directed care – absolutely not. It has always felt like a service-directed package – these are the restrictions and you just have to fit in with that.*

*(Partner of 67 year-old on Level 4 HCP)*

Participants described feeling 'overwhelmed' by having to choose a provider from 'hundreds of different providers' listed on the My Aged Care Finder website. They described comparing providers as time consuming. Some participants chose providers purely on cost because they did not know how to determine which providers had a good reputation.

*I had to put a spread sheet together. I spent days. There is no easy way to do a comparison. And a lot of providers don't put necessary information on the My Aged Care website. I had to make a lot of phone calls. I was comparing apples with oranges. I worked in corporate for 30 years and I struggled. God help those who aren't as savvy as me in doing that type of analysis.*

*(Daughter of 79 year-old on Level 2 HCP)*

**TABLE 3** Factors that are important to older people who receive a HCP

- Access to a competently staffed My Aged Care information line/web page to provide accurate and consistent information and advice;
- A clear explanation of providers' services, including their fees;
- Publication of providers' fees and charges on the My Aged Care website;
- Clear information about entitlements and reimbursements;
- Information on sub-contracted services, including rates and any additional charges;
- A home care agreement that is easy to understand;
- Reasonable fees for case management and administration;
- Reasonable charges for support workers;
- Support workers who are paid the award rate or above;
- Reasonable costs for equipment and home modifications;
- Reasonable charges for gardeners and other maintenance personnel;
- Clear financial statements that accurately reflect the services provided;
- Person-centred care delivered by a local provider;
- Support workers who are suitably trained, competent, trustworthy, punctual and empathetic;
- Knowledge about the qualifications and experience of staff;
- An option to choose support workers;
- Consistent support workers who work at regular and set times (eg 9AM rather than 'sometime between 9AM and 11AM');
- Flexibility with times and changing needs;
- Access to service provision "on the spot" (ie same day) when a situation changes (eg transport to a doctor's appointment);
- Sufficient time allocated for support workers to undertake tasks required;
- Direct communication permitted between recipient and support workers for easier co-ordination;
- A weekly roster of support workers supplied in advance;
- Case managers who are experienced, qualified and easy to contact;
- Consistent use of mutually agreed means of communication with case managers (eg emails, messages, home phone or mobile);
- Information about how many older people case managers are overseeing;
- Forward-thinking case managers who seek to improve care and offer suggestions if new services become available;
- Regular mandatory visits by case managers to include health/welfare checks, face-to-face conversations and updates with the older person;
- Better-trained office staff (eg training in talking respectfully to older people, including older people with dementia);
- Options for different degrees of case management support/self-management;
- Involvement of family/advocates when issues arise;
- Ongoing professional development, including dementia training, for all staff;
- Access to affordable social activities inside and outside the home;
- Provision of information from case managers on other community resources (eg local services, volunteer groups etc);
- Feedback from older people and their family/advocates welcomed by providers; and
- An effective complaints process.

Participants described receiving phone calls from providers soon after they were assigned a home care package. Some were offered incentives to encourage them to sign a Home Care Agreement with a specific provider.

*A provider I spoke with was offering a new Dyson vacuum cleaner if I signed with them. There is heavy persuasion going on.  
(Daughter of 75 year-old on a Level 4 HCP)*

Participants described providers' advertisements about what services they could deliver as 'misleading.' Some participants questioned why the government was giving HCP licences to companies with no expertise in the delivery of aged care services.

Participants were also concerned some providers accepted too many clients without hiring enough staff. This resulted in providers being unable to deliver the services they had undertaken to supply. Participants described making their provider deliver services as a 'battle.' They also described 'pulling teeth' and 'fighting' for their entitlements as 'exhausting.'

Participants who had their in-home care arranged while they were an inpatient in hospital said hospital staff recommended they use a large provider because large providers were less likely than smaller providers to 'go broke.' Participants who subsequently moved from a large provider to a smaller one said the smaller provider provided better, more person-centred care.

Participants understood the process of changing providers. No participant considered the exit fee an obstacle for changing providers. However, some participants were conflicted about changing providers. Although they described their current fees as 'excessive,' they had formed a good relationship with their support workers.

Some participants described a local provider being taken over by a large national company. They ended up with a provider they did not choose.

*You could start with an honourable company. But it gets taken over by a dishonourable company. I started with the council. I am now dealing with a large company. I did not choose this.  
(85-year-old woman approved for a Level 3 HCP but not assigned. Using CHSP)*

### 3.3 | Reasonable fees

There were significant differences between providers in both case management and administration fees, ranging from 9 per cent to 53 per cent of the government subsidy. Participants said it was difficult to know how much a service and equipment should cost without any benchmarks. They expressed concern at what they saw as inflated costs for labour, equipment and supplies.

Participants said they were charged a fixed cost for case management irrespective of how much case management they used. Participants on a Level 2 HCP questioned why they were charged \$400 to \$500 per month for case management and administration. In their opinion, organising three

hours of ongoing support per week (eg personal care, cleaning, shopping) required minimal case management.

There were also significant differences in hourly rates for support workers in the sample. The amount ranged from \$39 to \$65 per hour for a support worker on a weekday. Some participants asked their support workers what they were being paid. These participants noted the difference between what the support workers were being paid and what the clients were being charged.

Some participants were surprised by the small number of hours of support they received. For example, a participant with a Level 4 HCP (approximately \$50,000 per annum) received 14 hours of personal/domestic support per week. She said that she believed far too much money that was intended to support older people at home went ‘into providers’ pockets.’

Participants wanted clear financial statements that accurately reflected the services provided. Not understanding the financial statements was stressful for older people and their families. In addition, participants were charged for services they had not received.

*In our last statement, Dad had over \$2,000 listed as “Income Adjustment”. What does that mean? They also double charged us for some services. (Daughter of 88-year-old man on Level 4 HCP)*

### 3.4 | Case management

Participants described the case manager as integral to the quality of the service, particularly in the early days of receiving an HCP. They appreciated case managers who were experienced, qualified and easy to contact. They described forward-thinking case managers who sought to improve care and offer suggestions when new services were required.

Participants suggested regular mandatory visits by case managers to include health/welfare checks, face-to-face conversations and updates with the older person. Regular visits enabled case managers to arrange an assessment for a higher-level package when an older person's health deteriorated and/or needs increased.

*The case manager is very informative. She comes out once every three months to see how things are going. Each time she reminds me of things I am entitled to have. She recommends I leave my hours as they are so I can accumulate some funds to get the equipment I may need down the track. (70-year-old woman on Level 4 HCP)*

Participants described some case managers as ‘overworked.’ They said it would be useful to know how many older people a case manager was overseeing before they signed the Home

Care Agreement. Some participants said the HCP was meeting the needs of their parent/partner because a family member advocated on their behalf.

*It is meeting Dad's needs because I spend so much time advocating, checking everything, challenging the system and asking questions. Every day, I am doing something. If I wasn't here, I have no doubt that Dad could not stay at home. (Daughter of 88-year-old man on Level 4 HCP)*

Participants were grateful when they were able to form positive relationships with case managers. They considered themselves ‘lucky’ when they had the same case manager for a considerable length of time.

### 3.5 | Support workers

Participants valued support workers who were suitably trained, competent, trustworthy, punctual and empathetic. They wanted a weekly roster of support workers supplied in advance so they knew who to expect. They also wanted sufficient time to be allocated for support workers to undertake tasks required.

Participants complained about the large number of different support workers who were sent to work in their home. They said they were upset when a stranger turned up at their door. Some felt unsafe inviting strangers into their home. They were also dissatisfied when support workers did not arrive on time or, in some cases, did not turn up at all.

Participants appreciated continuity with the same support workers who came to their home at regular and set times (eg 9AM rather than sometime between 9AM and 11AM). However, they also noted the importance of flexibility with times when a client's needs changed.

Participants wanted to know support workers’ qualifications and experience. They were annoyed when young, inexperienced and untrained support workers came to their home. Three participants described the older person's family having to train a support worker to use a hoist (ie equipment) safely. This increased the stress not only for the older person and their family but also for the support worker. They recommended mandatory ongoing professional development, including dementia training, for all support workers.

### 3.6 | Person-centred care

Participants said an essential component of delivering person-centred care was good communication with providers, case managers and support workers. By ‘listening’ to older people and their families, providers were able to understand a

client's need for services and equipment. It also enabled case managers to match clients with compatible support workers. Participants indicated that large providers with a centralised administration were more prone to communication problems than small, local providers.

Participants suggested staff should receive specific training in both person-centred care (focused on shared decision-making and developing partnerships between support workers and clients) and consumer-directed care.

### 3.7 | Social engagement

Participants stressed the importance of access to social activities and community life. Participants on lower-level packages were able to access CHSP services at the subsidised rate. However, participants on Level 3 and Level 4 HCP said they were required to pay the full cost of Commonwealth-funded community social support activities. They had been told they could not 'double dip.'

Participants described the policy of 'full cost recovery' as preventing them from being involved in as many community social activities as they were prior to accepting a higher-level HCP. For example, a participant who accessed four local social activities every week for many years was forced to reduce his local activities when he transitioned from a Level 2 to a Level 3 HCP. This negatively affected his mental health.

*Sometimes I am so lonely, I don't want to live...  
I would like to continue to use council activities.  
They have bus trips and other clubs... But they  
are expensive.*

*(72-year-old man on Level 3 HCP)*

Participants also described the policy of full cost recovery as having a negative impact on people with chronic clinical needs who require daily nursing and/or allied health care. Some participants were advised not to accept high-level packages due to the increased cost of delivering these health services.

## 4 | DISCUSSION

Consumer-directed care requires informed consumers with access to reliable information. Participants with the best experiences had: (a) providers that charged reasonable fees; (b) case managers who delivered patient-centred care; (c) continuity of support workers; (d) a family member for support and advocacy; and (e) community engagement.

Previous research reported older people were satisfied with their HCPs.<sup>10</sup> However, evidence suggests most people are satisfied with their health-care service regardless of the quality of the care they receive—even those who have negative

experiences are satisfied with the care they receive.<sup>11,13,15</sup> This is particularly the case for older people. A US study of older patients found that level of satisfaction with health care is not a good measure of the quality or effectiveness of the health service.<sup>12</sup>

Kaambwa et al<sup>5</sup> found that participants prefer a consumer-directed approach that allows clients to choose the support workers who provide their day-to-day care, and to save unused funds for future use to; and allows support workers to be flexible in terms of changing activities. However, consumer-directed care requires access to reliable information to ensure consumers are well informed. Consistent with our findings, Kaambwa et al<sup>5</sup> found it is not possible to make informed choices without reliable information.

McCaffrey et al<sup>19</sup> identified features of consumer-directed care that older people value: (a) choice of provider; (b) choice of support worker; (c) flexibility in care activities provided; (d) contact with the service coordinator; (e) managing the budget; and (f) saving unspent funds. Day et al<sup>6</sup> found continuity of support workers was central to the development of a trusting relationship and perceptions of care quality among older consumers. However, providers that rely on agency staff do not provide continuity of care. In addition, person-centred care requires ongoing relationships with the same support workers.

McCallum, Rees and Maccora<sup>10</sup> identified a range of issues with HCPs that are consistent with our findings. These issues include the following: (a) waiting too long to be assessed, and having to accept a lower-level package until a higher one became available; (b) services being delivered at times or in ways that were inconvenient to the client; (c) a lack of continuity of care for older people with dementia and poor training for dementia care; (d) lack of duty of care and the occurrence of theft; (e) poor communication from the provider, and poor administration of services generally; and (f) failures in the delivery of consumer-directed care. Many of these issues can be attributed to poor case management and other staffing issues.

Participants expressed concern about the workload of case managers. They were also concerned about the number of unqualified, inexperienced and untrained support workers. In addition, findings suggest some providers do not hire a sufficient number of staff. Although the Commonwealth Department of Health reviews suitability of providers as per the criteria stipulated in the *Aged Care Act 1997*, participants described companies with limited or no expertise in the delivery of aged care services being given licences.

Findings indicated large differences among providers in both case management and administration fees and also hourly rates for support workers. This may indicate differences in the health needs of the older person and the complexity of providing case management and support. Alternatively, it may suggest overcharging.

The policy of full cost recovery ensures CHSP is able to provide a small amount of care and support to as many older people as possible (Commonwealth of Australia, 2018). The policy of full cost recovery recognises that HCP clients already receive government-subsidised services. However, this policy may result in older people on higher-level packages having limited access to social and community activities that were delivered by CHSP (ie subsidised by the federal government) which in turn can increase social isolation. Social isolation is one of the major issues facing older people in the industrialised world because of the adverse impact it can have on health and well-being.<sup>20-24</sup>

A limitation of this study is the relatively small sample. The aim was to conduct an exploration with extensive thematic interviews, and in this sense, our sample allows some confidence that a wide range of views were captured. However, the results of the study are not intended to be generalisable, nor was the sample representative in the standard scientific sense.

## 5 | CONCLUSION

This research provides important feedback about HCPs. HCPs have been designed to help older Australians remain in their own homes for as long as they can and wish to do so. It is imperative, therefore, that providers of in-home care deliver high standards of services that are both consumer-directed and person-centred.

Although the Commonwealth Department of Health reviews suitability of prospective providers against criteria stipulated, the findings suggest HCPs could be improved by tighter regulation of HCP providers, clear and regulated fee structures and simplified information statements to make comparison between providers easier, defined level of training for staff, consistent case managers and support workers, consideration of funds to ensure social engagement and review of full cost recovery. The policy of full cost recovery limits access of older people to social and community activities that they previously received under CHSP, which may increase their risk of experiencing social isolation.

Rather than have funding for HCPs capped at a certain level, HCPs could be funded to reflect the client's goals and individual needs. This would remove the need for clients to choose between receiving allied health, personal care, home care, home modifications and equipment and social support, which often results in clients being socially isolated because they are not able to afford social activities.

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## CONFLICT OF INTEREST

No conflicts of interest declared.

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