

The invisible contract: shifting care from the hospital to the home

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Abstract

The ageing population and associated burgeoning health care costs have resulted in a shift of care from institutional settings to home and community-based care. As one example, rehabilitation-in-the-home (RITH) programs are becoming increasingly prevalent. These programs either substitute or supplement in-hospital treatment by providing multidisciplinary rehabilitation and support services in the client's own home. This paper investigates the impact of RITH programs on informal carers. Semi-structured interviews carried out with caregivers and staff revealed a complex and contradictory interpretation of informal caring. Analysis of carers' interviews revealed: an assumption by themselves and others (including RITH staff) that they would provide care; the intimate, arduous and relentless work of caring; lack of consultation about discharge; lack of recognition and reimbursement; and low levels of program support for them as carers. Carers are integral to the successful rehabilitation of the client, but they occupy a marginal status within the program. An invisible contract consigns to them substantial care-work that was previously provided by the hospital. Informal carers in RITH programs can be seen as disenfranchised care contractors. This has implications for policy makers, program managers and researchers.

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What is known about the topic?

Rehabilitation-in-the-home (RITH) programs are an example of a shift in health service delivery from institutional to community-based care. Clients in bed-substitution RITH programs are technically still hospital inpatients. Little is known about the implications for family members or friends who provide care for clients in these programs.

What does this paper add?

This empirical, qualitative study revealed that carers are integral to the successful rehabilitation of the client, but they are consigned a marginal status within the program. An "invisible contract" binds them to carry out substantial care-work that was previously delivered by hospital staff. Carers are poorly compensated, and largely excluded from decision-making processes.

What are the implications for practitioners?

Practitioners should develop an explicit statement of the expectations, rights and entitlements of carers involved in home-based rehabilitation programs. Program protocols should formally incorporate carers into case planning and review processes. This documentation could be used by carers to support their applications to government departments for carer payments.

WITH A RAPIDLY AGEING POPULATION, governments in the developed world have become increasingly concerned with managing the burgeoning costs of health care. One widespread strategy to contain the cost of health care has been to reduce the time that older people spend in hospital and substitute hospital care with home-based acute and sub-acute health services.^{1,2} Rehabilitation in the home (RITH) is an example of this shift in health service delivery. RITH is a relatively recent model of health service delivery. The first Australian program was established in 1995.³ RITH programs can be divided into two types: those that aim to replace hospital rehabilitation (bed substitution); and those that aim to complement inpatient care (ambulatory).

In both program types, a multidisciplinary rehabilitation service is largely provided in the client's own home, rather than in hospital or in a community rehabilitation centre.⁴

Based on interviews with carers and interviews and surveys with RITH staff, this paper describes a recent empirical study of informal care in RITH programs in Victoria. The authors argue that, in transferring rehabilitation from hospital to home, care responsibilities have been shifted from paid staff to unpaid carers. These unpaid carers are relied upon by the state and by hospitals for the provision of home-based rehabilitation, yet they are not considered as members of the rehabilitation team. This means that their work is largely unrecognised and uncompensated and they have little say in care-planning decisions that impact upon their lives. It is argued that this unwritten obligation carries no reciprocal rights and constitutes an invisible contract between informal carers and the state.

Literature review

Rehabilitation in the home has been evaluated in terms of patient outcomes,⁵⁻¹⁰ participant satisfaction,^{11,12} and cost effectiveness.¹³ Research findings show that home-based rehabilitation results in functional outcomes that are as good as, if not better than, hospital-based care, that clients prefer home to hospital-based rehabilitation and are generally satisfied with the care they receive at home.

Investigations into the cost effectiveness of RITH programs show mixed results. A meta-analysis of randomised controlled trials calculated that the overall costs were about 15% lower for the early discharge interventions compared with conventional care.⁵ However, this calculation did not include carer costs and was based on potentially incomplete accounts of service use and therapy sessions. Only three studies included carer time, and/or loss of earnings in their analysis of the relative costs of hospital and home-based care.^{8,13,14} Two of these found that when carer time was considered, home-based care was not cost effective compared with hospital care.^{8,13}

One of the most comprehensive cost analysis studies (including both direct and indirect costs) concluded that there had been some cost shifting from hospital to the primary care system in the provision of home-based care.⁸ These results have been supported by a study that found that there was some cost-shifting associated with home-based rehabilitation,⁵ although others have found home-based rehabilitation to be less expensive than hospital rehabilitation even when carers' time was included in the analysis.¹⁴

The primary focus of the research on carers in home-based rehabilitation has been on carer stress. Most studies comparing carer stress in home-based with hospital-based rehabilitation found no difference in carer outcomes.^{12,15-18} However, two studies found home-based rehabilitation to be associated with poorer carer outcomes,^{19,20} and one with better carer outcomes.²¹ To date, only one study has examined the amount of work that carers have been required to undertake, and the impact that this has on their lives.²² Therefore, the research question addressed in this paper is: how is the role of the carer constructed in RITH programs?

Methods

The research took place in Victoria, Australia where nine bed-substitution home rehabilitation services were operating and eight services agreed to participate. These eight services provided a multidisciplinary rehabilitation service, case management, and service brokerage. All relied on the client's general practitioner for daily medical management but had access to a specialist in rehabilitation and/or geriatric medicine if required. Five of the services were based in metropolitan Melbourne; one in an outer-metropolitan area; and two in country Victoria. The study was approved by each hospital's and the researchers' university human research ethics committees.

There were three main research methods employed in this study: individual, semi-structured, tape-recorded interviews with caregivers about their lived experiences; semi-structured,

Demographic characteristics of carers interviewed and care recipients

Interview number and pseudonym	Carer		Care recipient		
	Relationship to care recipient	Age	Diagnosis	Sex	Age
1 Amy	Niece	60s	Fractured pelvis	F	84
2 Paula	Daughter	47	Fractured pelvis	F	84
3 May	Grand-daughter	29	Hip replacement	M	78
4 Frances	Friend	30s	Fractured hip	M	80s
5 Bea	Daughter	50s	Fractured hip	F	95
6 Lisa	Wife	50s	Stroke	M	63
7 Judy	Wife	20s	Amputation	M	24
8 Bernadette	Daughter-in-law	50s	Surgery for cancer	M	87
9 Sally	Daughter	30s	Bowel cancer	F	67
10 Ernie	Husband	74	Parkinson's disease	F	74
11 Anna	Wife	60s	Stroke	M	72
12 Ruby	Wife	74	Bowel cancer	M	77
13 Rose	Wife	65	Total knee reconstruction	M	60
14 Ivy	Wife	70s	Amputation	M	Unknown
15 Gwen	Wife	80	Fractured ribs and shoulder	M	82
16 Julie	Wife	50s	Parkinson's disease	M	70
17 Emma	Wife	80s	Stroke	M	84
18 Heidi	Daughter-in-law	30s	Fractured hip, cancer	M	64
19 Fred	Husband	78	Stroke	F	78
20 Carol	Wife	60	Stroke	M	63
21 Dave	Son	53	Fractured hip	F	91
22 Jill	Wife	60s	Stroke	M	63
23 Freda	Wife	50s	Brain tumour	M	62
24 Ingrid	Wife	88	Hip replacement	M	89

group, tape-recorded interviews with program staff about their perceptions; and surveys of program staff about clients and carers. The interviews with carers were held in their own homes. The carer was given a choice as to whether they would like the care recipient present, and four carers chose to include the care recipient. In only one of these four interviews, the presence of the care recipient seemed to limit the carer's ability to speak freely. The staff group interviews were conducted in the workplace. The surveys were conducted face-to-face with staff who had a case management role within the RITH program. They were asked to

complete a de-identified survey for each person on their caseload who had a carer.

Carers were defined as family members or friends who were providing care for a client of a home-based rehabilitation program where there was a transgression of the usual expectations. The carer could be co-resident or living elsewhere.²³ A total of twenty-four carers were interviewed over a 9-month period. They were recruited from one home-based rehabilitation program from a regional city. Although the recruitment of interviewees was conducted within a single program, potentially limiting the generalisability of the study findings, this program was no different in

its model or service delivery to the other seven programs involved in the study. It was therefore expected that the experiences of carers in this program could be representative of carers in any Victorian bed-substitution RITH program.

Case managers working in the home-based rehabilitation program were asked to invite all carers to take part in the study. Of the 60 carers involved in RITH during this period, 36 (60%) agreed to have their names and addresses supplied to the researcher, and 24 agreed to be interviewed (40% of total sample). Twenty-one female and three male carers took part in the study. The female carers included 13 wives; three daughters; two daughters-in-law; a friend; a granddaughter; and a niece. The male carers were two husbands and one son. The average age of the carers was 50.4 years, with most being in their fifties or sixties. The age range was 23 to 88 years. Eleven carers were additionally engaged in either paid or voluntary work, and two were studying full-time. Six carers (all women) had dependent children and/or other dependent adults to care for. There were 23 clients receiving care from the 24 carers. The clients ranged in age from 24 to 95 years. Most required rehabilitation for orthopaedic or other surgery; eight had a neurological condition; and three had cancer. Seventeen of the care recipients were male and six were female. The Box shows the demographic characteristics of the carers interviewed.

The tape-recorded interviews with the 24 carers were transcribed and subjected to both content and thematic analysis. The content analysis was based on the questions asked about the type of care provided, the impact providing care had on the carers' lives and their interaction with formal and informal support services, including the hospital from which the care recipient had been discharged and the RITH program. The transcripts were also thematically analysed. As a participant check,²⁴ carers were then sent an overall summary of the interview themes and the researcher's interpretation. All eight who responded indicated that the findings and interpretations reflected their experiences.

Surveys on 102 clients and their carers were completed with case management staff from the eight programs. These surveys included questions about the demographic characteristics of the client and carer; the extent and type of care undertaken; and the services received by the client and/or carer. Program managers and case management staff were also invited to participate in an interview. Twenty-three agreed to be interviewed about their policies and practices with regard to carers. The tape-recorded interviews were thematically analysed. Within 1 month following data collection from each program, a detailed summary report was sent to the program manager for distribution to the staff and verification. They were requested to inform the researcher if they did not agree with the way in which the findings of the interviews had been interpreted and/or if there was anything they wanted to add. There was no response from program managers or RITH staff.

Results

The carers' accounts of their experiences in the RITH programs are outlined below. Their experiences are structured around five themes: the assumption of care; the work of caring; confusion and lack of consultation about discharge; lack of reimbursement and recognition; and support to carers. The names of carers have been altered to maintain anonymity. The staff perspectives that relate to the themes derived from the carer interviews are also presented.

Assumption of care

Carers were asked about how they had come to take on the role of carer. For many, it seemed to have happened almost involuntarily, without conscious deliberation or intention. For example, one carer said "It just happened". Another said "When her health went down a bit I just automatically stepped in to do a little bit to help her out." However, it was not always easy for this transition to occur. The carer who said "It just happened" was referring to the fact that her father-in-law had moved in with her and her husband and two

small children after he had had a total hip replacement and surgical and chemical treatment for cancer.

It was also “assumed” by others including program staff that the carer would take on the role. There was not always a formal process of identifying the carer within the RITH programs. Although there was generally a place on the admission form for identification of the next of kin, this was not necessarily the carer. Staff reported that carers tended to be identified either by staff as the person most often visiting the care recipient in hospital, or by the care recipient.

Although there was no formal requirement that clients admitted to RITH have a carer (unlike hospital in the home, in which the availability of carer support is a prerequisite to admission), most program staff acknowledged that they relied heavily on the carer in the provision of rehabilitation at home. They reported that many clients would not be discharged home for rehabilitation without the support of the carer. Carers also reported that they did not have a choice about the discharge of the client to home (and into the RITH program).

Perhaps the lack of consultation about discharge can be partially explained by the lack of formal carer identification. It is more difficult, given the pressures upon hospital staff, to include carers in consultations about discharge if they have never formally been identified, let alone recognised as playing a key role in the discharge plan.

The work of caring

The carers were asked about the care that they provided immediately post-discharge from hospital during the time that the care recipient was a client of the home rehabilitation program. Eighteen of the 24 carers said they were providing care 24 hours a day. For seven of these carers, this meant they not only had to be there 24 hours a day but they were doing care-work around the clock (for example, getting up several times at night to help the care recipient get to the toilet, or to move them to prevent bed sores). Most carers assisted the client with domestic activities of daily

living. Slightly fewer helped with personal activities. Fifteen carers assisted with rehabilitation activities and six were involved in nursing tasks such as wound care or diabetes monitoring. Twelve carers reported that their responsibilities had diminished over time, seven said they were about the same, and five reported that their caring responsibilities had increased since the time immediately post-discharge from hospital.

The expectations that staff had of carers were consistent with the carers’ descriptions of their caring activities. Staff said that carers were mainly expected to provide assistance with domestic activities of daily living, such as cooking, cleaning and laundry, but they were also relied upon to monitor the client’s safety at home, follow-through on therapeutic regimes, and to a lesser extent, provide assistance with personal care. One staff member described her program’s expectations as: “A lot of encouragement and support, their OK [for the client] to come home, looking after the physical situation, providing the meals and the hotel-type support.” Other expectations were that the carer cooperate with the rehabilitation team’s care plan. Staff said they expected the carer “to work as part of the team” and “to be compliant, cooperative and amenable and if they’re not they are often labelled difficult, resistant and obstructive.”

The work of care during the RITH admission was often intimate, arduous and relentless. For example, one carer described how showering and dressing her husband was a round-the-clock task: “It took nearly all day because he would wet himself and I would have to change him . . . It was all I did . . . (and at night) I’m up four or five times a night rushing to get a bottle for him . . . I don’t get a lot of rest of a night time.” Most carers said that their concern about the care recipient was with them constantly even if they were not constantly with the care recipient. Errands, work commitments, medical appointments, and anything else that took them away from the caring role were uneasy outings. For example, one carer said of running errands: “I would be on edge, I’d go down the street but think, ‘Oh, I’ve got to get home’”. Another carer described her visit to the

doctor: "I had to go to the doctor's but she's only around the corner and that only (meant) I left him for about forty minutes. I said to him 'You stay in your chair and don't get out.' Well he didn't need to get out. He had his bottle beside him if he needed to do urine."

Confusion and lack of consultation about discharge

Carers were somewhat cynical about the extent to which discharge was in the best interests of the client. They perceived that discharge sometimes had more to do with the needs of the hospital than the patient. They also reported that discharge from hospital to home was not always adequately planned. There was inadequate time for consultation about the care recipient's needs and to prepare themselves to take on the care required.

Paula described her mother's discharge as "getting rid of her out of hospital." Judy said that "They didn't want a staph infection from the (hospital) in their ward", referring to the fact that her husband had contracted a *Staphylococcus* infection while in another hospital. May felt that her grandfather should have stayed in the rehabilitation ward longer, but was discharged due to a shortage of beds. She said: "I didn't feel that he was ready to be out of the care system and my view is that he should have gone to (the inpatient rehabilitation facility) and had a week there for his own emotional security."

Some carers felt that the discharge from hospital was rushed or premature. Dave said: "The [pre-discharge] home visits were too early ... they brought her home the following week and they admitted it was too early and it caused a fair bit of trauma with her." Gwen's husband had had to be readmitted to hospital. He said: "... they shouldn't have sent me home ... I was in terrific pain ... they had to take me back in the middle of the night."

The other main problem associated with discharge for the carer was the lack of consultation with them. As Judy stated: "No-one told me beforehand or gave me any warning that he was going to be coming home." Heidi was perplexed

by the discharge processes from both the hospital and RITH. She said:

No, I still didn't know that he was coming home ... I don't know if they had a spare bed they would keep him. I don't know. It's really strange how it works ... And they will say "He is coming home today" and then they will say "No, he's not".

The staff interviewed reported that they were under pressure to discharge clients to home as soon as possible. RITH was one program that could provide a high level of post-discharge support at home. Therefore, RITH programs were referred not only those people with conditions considered to be responsive to rehabilitation, but older frail people with a range of comorbidities. This placed additional pressure on the staff, and they acknowledged it also meant carers were caring for clients who were often frail and medically vulnerable.

Lack of reimbursement and recognition

Very few of the carers involved in this study received a Carer Payment or Allowance. Those that did experienced problems associated with carer payments, including lack of information, and trouble establishing eligibility. Several carers said they had not been informed about these benefits or they were unsure about what they were being paid. For example, Anna said in relation to carer payments: "I wouldn't have a clue ... I haven't asked anyone and nobody has said anything to us." Julie said that she did get an allowance; she didn't know its name but that it was \$82 per fortnight, and "... we only just not long ago got that ... we didn't even know about that."

Some carers were ineligible for the Carer Payment as they received other income and for some, like Bea, this seemed particularly unfair. She had contributed to her own superannuation fund during her working life because employer-funded superannuation had only been offered to male employees, and the income she now received from her self-funded superannuation made her ineligible for the Carer Payment. This was despite

the fact that she spent all her waking hours, and interrupted nights, caring for her mother who would otherwise have had to go into a nursing home. Undertaking paid work also created eligibility problems for carers receiving the Carer Payment. For example, May found that if she worked one day per week, she had to spend another day rearranging her entitlements for the Carer Payment. Those who did receive the Carer Allowance considered it inadequate. Dave said:

I've just applied for and received the Carer's Allowance. It's a pittance ... If I had been paying (for a personal alarm system), that's \$15 a fortnight. Taxis ... and everything — \$40 a week ... there is nothing left. Financial assistance is just totally inadequate ... If everyone was in care with the government (it would) cost them \$70 000 a year and I am doing it for \$2000. I think they are doing pretty well.

Support to carers

The carers interviewed were asked about the supports that they received from family and friends, from the home rehabilitation program, and from community services and whether they perceived them to be adequate. All clients received visits from one or more rehabilitation staff; most were visited at home by their general medical practitioner during the rehabilitation program; 13 were visited by the district nurse and 11 and 10 received Meals on Wheels and Home Care, respectively. All services were brokered (organised and paid for) by the home rehabilitation service and carers were generally satisfied with the adequacy of these services.

Carers expressed appreciation of rehabilitation and community support services. However, they also expressed confusion about these services, and frustration at the lack of consultation and information provided to them about care planning, and discharge decisions. Despite the critical importance of the carer in the provision of home-based rehabilitation, no RITH programs had any formal processes of identification, recognition, inclusion or compensation for the carer. Staff generally regarded carers as part of the client's

support network and they were included in the assessment process to determine what they could and could not do for the client and therefore what services had to be brokered in for the client. However, important decisions, such as when to discharge the client from hospital, were often presented to the carer as a *fait accompli*, rather than matters to be negotiated. One staff member described the communication with the carer in the following way:

(I don't think) we involve the family and the carers in the actual formulation of the decision about whether the person will go home or not. We make our recommendation then we inform, sometimes. Sometimes I've heard that clients in the ward have a 3-week period of time when we're doing our assessment in determining the level of care. At some point, suddenly, the staff start talking to the client about "Oh, it's great, you're going to go home. Now we're going to start doing home visits and we've got to get you mobilised because you've got three steps at home." The family asks "What has happened? All of a sudden Mum has told me she is going home. I know nothing about this. What's shifted? Something dramatic has happened and I don't even know about it. I've got to unlock the house. I've got to get the cat back. I've got to be available. When is this happening? I've got to be at home for the home visits. When did this shift take place and why didn't I know about it? Because this has huge implications for me. My daughter has just had a baby and now they tell me that Mum is coming home ... " It's very paternalistic still and we get challenged on it when people complain but we don't have a strategy at the moment for dealing with it proactively as part of standard client customer service.

Furthermore, the essential knowledge that the carer had about the client's care needs was not routinely sought. One staff member recounted a story of working with a client on meal preparation only to discover (from the carer) after a few frustrating sessions, the client had not even

boiled a kettle for some years before her latest stroke.

Many staff believed that this lack of consultation with carers was a shortcoming of their program, but they also felt that there was no time (due to the constant pressure to accept new referrals) to get to know the carer and to properly include them in the care planning process. A staff member said:

I don't feel that I am practising satisfactorily on a number of levels. It's just having to do a lot in just a few hours . . . Most of mine are only on [the program] for about three weeks . . . by the time you try to build up rapport with the client and carer (and they're quite busy at the same time) you're just getting to know them and they are off the program.

Discussion and conclusion

A unique aspect of this study is the triangulation of views from both carers and staff involved in RITH programs. There was a high degree of convergence between staff and carers' description of the role of carers in RITH. Both perceived that carers were taking on a high level of work and responsibility in home-based rehabilitation with little financial compensation and overall a low level of service use. Furthermore, both carers and staff perceived a problem at the interface between the carer and the service system in both the provision of information and the inclusion of the carer in the decision making about client care. Some of the problems experienced by carers in this study are not unique to RITH. Pressures to discharge patients quickly from hospitals can result in inadequate discharge planning. However, the RITH program provides a safe and convenient care environment to which vulnerable patients can be discharged, and therefore carers and staff in RITH are often left to deal with the consequences of inadequate discharge planning.

It has been suggested that the three main contexts of care-giving are the household, unaffiliated providers and formal organisations.²⁵ With the shift from institutional to community and home-based care, these boundaries are blurring.

The carers involved in this study were not just operating in the household mode or setting. The clients for whom they were caring were technically inpatients of a hospital, and therefore located within the bureaucratic, or formal, organisational setting. The model of rehabilitation that was implemented in the home was developed in a hospital setting and the processes and decisions relating to admission, care planning and discharge were largely unchanged in the home. With RITH the traditional hospital model of rehabilitation has been shifted into the home without regard for the private and individual nature of that space. Therefore, a new context of care has been identified in this study, one that sits between the household and institutional settings identified in earlier research.²⁵

This study also contributes to the small but important body of interpretivist research on the geography of caring. These findings qualify conceptualisations of the home as therapeutic landscape.²⁶ Caregivers in the RITH program did not experience their home as a therapeutic setting. Home was translated into a site of labour, personal sacrifice, and loss of control. Private spaces were commissioned as public. Informal, personal support became redefined as quasi-professional tasks to be administered as part of a care plan.

Most caring research focuses on long-term care and care of those with chronic illness or disability. In the early phases of this study, it was assumed that the care-giving episode for both the home-based rehabilitation client and his or her carer would be short term. It was also anticipated that the carer would feel encouraged by observation of the care recipient's physical improvement and the expectation that the episode of care would be time limited. Although these assumptions and expectations were borne out in the experiences of some carers, for the majority they were not.

These findings call into question the way in which rehabilitation is generally defined and the implications this has had for the way that home-based rehabilitation programs have been established. Intensive rehabilitation of the type that is provided through home-based rehabilitation programs is usually only provided on a short-term

basis, to a maximum of eight weeks. This is based on the notion that rehabilitation is a restorative process rather than a supportive or palliative one. However, as both the carer and staff interviews suggest, many clients discharged from inpatient care into RITH were not expected to make a full recovery or to rapidly improve. We are not arguing that these people should not be offered the benefits of a home rehabilitation program, but rather that their other care needs be acknowledged and better catered for by the health service. However, it is also recognised that this is difficult in the context of increasing pressure to discharge older people from hospital and increase throughput, which appeared to be one of the ways in which RITH was utilised.

In home-based rehabilitation the carer was in a central position as far as the work and responsibility for care was concerned, but in a peripheral position in decision-making power. Although carers were a critical component of the package of care provided to the RITH client, they did not see themselves (and they were not treated) as fully participating members of the RITH team. This was recognised as a problem by both carers and staff in this study. Some of the staff interviewed for this study indicated that they would like to involve the carer more as an active participant in the decision-making process than they have been doing to date. The main impediments to this seemed to be time and workload constraints. Staff were under pressure to facilitate early discharge from hospital and to increase throughput in home-based rehabilitation. These pressures constrained their ability to treat carers as co-workers.

Furthermore, the expectations, obligations and rights of the carers were not made explicit. Informal carers in rehabilitation in the home programs can therefore be seen as disenfranchised care contractors. An invisible contract consigns to them substantial care-work that was previously provided by the hospital.

Given the prevalence of the home-based substitute as a model of health care provision and the reliance of these programs upon the work of informal caregivers for positive client outcomes, it is essential that health services address the issues

that have been raised in this study. Firstly, the expectations that home-based programs have of carers should be made explicit to the carer, together with any reciprocal rights and entitlements. This could be done in the form of a written agreement. This agreement could serve a number of purposes. It could make explicit the mutual expectations of the staff and carers in home-based rehabilitation, and give carers written information about the community support services that would come into the client's home. It could also serve as a data collection tool for documenting the expected contribution of carers in home-based rehabilitation. These data could then be used by carers to apply for carer payments provided by government departments. Secondly, program protocols should be reviewed so as to formally incorporate carers into case management planning processes. Finally, in order to further illuminate and appreciate the work of unpaid carers, future research into cost effectiveness of home-based substitute programs should develop more comprehensive and inclusive measures of the direct and indirect costs of carer contributions.

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Competing interests

The authors declare that they have no competing interests.

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