

Assistive devices: self-reported use by older people in Victoria

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Abstract

A qualitative study was conducted in Victoria to explore factors affecting the acceptability and use of assistive devices by older people. Four focus groups and fifteen home-based interviews were conducted with older people (mean age 77 years) who had been issued with 2 or more assistive devices. Analysis of the data indicated that almost all participants were content to be advised by professionals on suitable equipment. Most considered the equipment and home modifications safe and easy to use, and appreciated the benefits for mobility, confidence and independence. Reasons for non-use were commonly related to changes in functional ability. Cost was a major deterrent for a small number who opted to 'make do'. Recommendations are made for improvements to the existing system of equipment provision and use, including: review and development of consistency of provision and payment policy among service providers; flexibility of payment options; adequate education and follow-up support for clients.

Literature review

Assistive devices are aids and appliances designed to improve functional ability for people with disabilities (George et al. 1988). Some studies have found that the use of assistive devices increases independence and reduces the need for personal care (Parker and Thorslund 1991; Gitlin and Burgh 1995). In Australia, the use of assistive devices has rapidly increased: between 1981 to 1993 the number of Australians with mild activity restrictions using an aid to assist their mobility increased from 32,500 to 118,100 (McInnes et al. 1994).

Mechanisms for the provision of assistive devices vary both between and within each of the Australian States and Territories. For example, in Victoria, the Program of Aids for Disabled People (PADP) is a government program that provides a range of devices to people who have a permanent or long term disability or are frail aged. The program has a set list of aids and appliances and a ceiling price for each item. Current policy requires a non-refundable contribution from the client when the device costs more than the program's allocated ceiling limit (Department of Human Services 2000). Policy also states that PADP providers are required to monitor and review the use of the allocated device and ensure that training is provided in the correct use of the equipment. Reusable items when no longer needed should be returned to the PADP provider (Department of Human Services 2000). Assistive devices are also available free of charge to eligible veterans, from some public health services or for private purchase or rental.

Different studies indicate varying degrees of use of assistive devices. A review of 11 studies found usage rates ranging from 46% to 87% (McInnes et al. 1994). A number of international studies have considered the use of

assistive devices and reasons for people not using these devices. A change in functional status is a common reason for ceasing use of assistive devices, whether that change is due to an improvement or decline in function (Parker and Thorslund 1991).

Literature investigating the non-use of devices that could still be beneficial to the recipient tend to concentrate on the negative perceptions of using devices, which are linked to the societal stigma associated with disability and ageing. Hocking(1999) explains that the use of a device can negatively impact on a person's perception of self in the context of the values of their society. Focus groups held with older people living in Britain found that barriers to using assistive devices included perceptions of not needing the device, or denying the need, feelings of embarrassment, and cost. The use of walking sticks had additional barriers such as stigma, pride, fear of dependence and not knowing how to use it when compared with bathroom devices (Aminzadeh and Edwards 1998). The issues of pride and dependence may be more salient with the use of a device that is used publicly compared to the private use of bathroom devices. Another study of the perceptions of older people found that the benefits of mobility devices for promoting independence far outweighed the stigma associated with the appearance of devices (Pippin and Fernie 1997). These studies also found that some people appreciated the 'special treatment' that they experienced when using a mobility device.

Other reasons to explain non-use of assistive devices relate to practical issues, such as receiving an aid weeks or months after the need has been identified, or lack of instruction in its use (Chamberlain et al. 1978). Some studies have pointed out the importance of involving consumers in the design and process of issuing devices (Ryan et al. 1996), so that problems can be identified and addressed. A study of older people and their use of assistive devices provided at discharge from a rehabilitation setting found that the most important factor predicting use was the person's expectation that they would use the device when they got home (Gitlin et al. 1996). Actual level of functional independence did not appear to directly influence use. Personal differences and expectations also need to be considered. For example, some people may prefer to receive personal care than to use technical aids because of the importance they place on social and human contact (Mulley 1988).

In Australia, there has been an absence of recent studies that have considered satisfaction with the use of assistive devices, or reasons for not using them. A study by Matthews et al. (1991) considered the use of blood glucose meters in the management of diabetes mellitus supplied through the Program of Aids for Disabled People (PADP) scheme. The study raised issues of maintenance of records to enable follow-up and the need for health professionals to conduct routine review of the use and accuracy of devices. The study did not explore the opinions and experiences of people issued a blood glucose meter, and therefore was unable to explore why almost one third reported using it infrequently, if at all. A study of hearing aid use in women in Sydney found that only a third (34%) of those who had been advised to wear a hearing aid were regularly using it, but users were those who were more likely to access community services (Mulley 1988). These studies suggest that use of assistive devices may also be low in Australia, but do not shed light on reasons for non-use. The present study reported here, which explores older people's perspectives on use and satisfaction with devices, in the North Western Healthcare Network in Melbourne, was conducted in order to examine some of these issues. With a move to user pays schemes, and lengthening waiting lists for public systems providing free or low cost equipment, we considered a review of equipment provision was warranted. The specific study aim was to conduct a pilot study to explore factors that affect the acceptability of assistive devices by older people and hence influence their use of such aids.

Method

This qualitative, descriptive study used focus group methodology (Quine 1998) and a structured home-based interview to identify issues for older people relating to the provision and use of assistive devices. Focus group methodology has been used effectively with older people (Quine and Cameron 1995), although additional effort is required to organise such groups if participants are frail and/or physically disabled. Focus groups are useful for "... collecting background information or identifying issues that will form the basis of hypotheses, more structured questions, evaluations or needs assessments" (Grbich 1999, p108). It was therefore identified as an appropriate methodology for use in exploring the issues around assistive device prescription and use with this older, disabled population. Focus group methods have some limitations. For example, it is difficult to explore

questions in detail, the views of two or three participants may dominate and "... the 'public' rather than the 'private' views of individuals tend to be documented" (Grbich 1999, p115). To address these limitations, individual home-based interviews were used to supplement the information obtained through the focus groups.

The participants for the study were drawn from the Aged Care and Rehabilitation Program of the North-Western Healthcare Network (NWHCN). This is a large network of health services including acute services and inpatient, outpatient and community based aged care. A sample was selected from the community rehabilitation and government funded equipment provision service clientele of the network who satisfied the selection criteria (below). The aim was to include a range of people who had been provided with equipment from different funding sources, as cost may be an issue affecting use. NWHCN ethics clearance was obtained, and it was specified that any issues of safety or concern identified in the study were (with the client's permission) to be referred back to the treating therapist or service.

There were three main sources of study participants: clients of PADP, clients currently attending a community rehabilitation centre of the NWHCN, and clients who had received assistive devices whilst inpatients of NWHCN Aged and Rehabilitation program. Selection criteria included 60 years and over; English speaking; no significant cognitive impairment – (based on medical record data and clinical report); two or more assistive devices issued for at least two months (to provide an opportunity for routine patterns of use to be established); and residing in geographic catchment area of the NWHCN.

Clinical staff screened the potential participants and made telephone contact with those who were eligible to ascertain verbal agreement for participation in either a focus group or a home based interview. Once verbal consent was obtained, written information was provided to the potential participants including a formal letter of invitation to participate, a plain language statement and consent form meeting the specifications of the NWHCN Research Ethics Committee. 40 people met the study criteria and agreed to be involved in the study. Sampling was conducted progressively, and recruiting for both the focus groups and the home-based interviews ceased when no new information was obtained, known as 'saturation point'. Basic demographic information and details of assistive devices for each focus group participant were collected prior to the commencement of each group and as part of the interview procedure for those participating in the home-based interview.

Twenty-five people participated in one of four focus groups. These were conducted in a meeting room at one of the NWHCN campuses. Transport assistance was arranged for participants as needed and refreshments were provided. One of the research team (SQ), with extensive experience conducting focus groups, was facilitator for all groups. The other researchers alternated in the role of scribe. The following issues regarding assistive devices were raised: use, choice, methods of provision and follow-up, recycling, loan and cost. Each focus group ran for approximately one hour. Group discussions were tape-recorded and comprehensive notes taken by the scribe that related to both the content and dynamics of the group (Quine 1998).

Fifteen people participated in home-based interviews. One researcher (JA) – an experienced Occupational Therapist – took the lead role in the home-based interview process. Each interview lasted for approximately 70 minutes. A standard interview format and recording sheet was devised for use in the project. This drew on home assessment forms used in clinical assessment for the recording of assistive device information and was aligned with, and expanded on, the prompt questions explored in the focus groups. The researcher undertook a tour of the house – with the participant if possible – and noted all assistive devices present. Participants were asked about their acquisition and use of each device.

Analysis

The tape recordings of the four *focus group* sessions were transcribed and the data analysed for each issue discussed. A similar range of responses emerged in each group. Saturation point was reached by the third group, with no new information emerging in the fourth. The data were summarised by the facilitator (SQ) and verbatim quotations used for illustration. The summarised findings were independently reviewed by the scribe for accuracy, thereby enabling a reliability check.

The demographic and descriptive information from the home based *interview* data were tallied and summarised by the occupational therapist (JA), who also analysed the content of the information obtained on the home visits. Key themes were identified and summarised. A second researcher (RS) reviewed the original information

and summaries independently. From a comparison of their independent notes, consistent themes emerged, indicating that there was no need for a third review of the data. Participants' quotes were extracted to illustrate key points.

Results

All participants were community dwelling and approximately half were living alone. The average age was 77 years (for both males and females, with a range from 65-94 years). Three quarters of the sample were female. A variety of diagnoses and medical conditions were reported including stroke, fractures, arthritis, and Motor Neurone Disease.

It became evident that, although these participants were selected on the basis of assistive devices provided through a particular hospital linked program, they had obtained assistive devices from multiple providers. These included self, family, community service providers, pharmacies, local government and other public hospitals. The number of providers per participant ranged from two to six (mode: three). When multiple providers were involved, participants frequently had some difficulty recalling who had provided specific pieces of equipment. There had often been a history of acquiring equipment over a number of years. There was wide variation in the number and range of assistive devices provided (from 5 to 15). There was also a combination of free, purchased and rented equipment. Items acquired free of charge came from two main sources: previously used items from family/friends, and items supplied by a health service free of charge. There was variation in the proportion of equipment that was self-funded. In general, people were more likely to have paid for their small aids and equipment (eg: dressing aids, kitchen items) than for large, more expensive items (eg: electric wheelchair, specialised lounge chair) and grabrails.

Cost

The cost of items was an issue for the majority of participants in both the focus groups and the home based interviews:

"I have to think of it (cost). I must be honest. I have a husband in a nursing home which costs me money."

Participants indicated a desire for greater flexibility of payment options such as instalments or co-payment schemes:

"I can't afford to pay a lot of money for one item."

This was particularly important as most participants were on a limited income or a government provided pension. In general, people did not expect to receive items free of charge, stating that they were prepared to pay at least part of the cost.

A small number of people reported refusing items, or had delayed obtaining items or 'made do' with inferior items due to cost. There were also hidden costs that were difficult for some people to meet, such as maintenance of equipment, installation of a power point for scooter recharging and other accessories (crutch holder, cover for scooter, basket etc).

Choice of equipment

Participants were asked about their degree of choice, a question that was initially difficult to answer for most people. On exploration, it appeared that participants were not presented with a choice about whether assistive devices were needed or not. Rather, the need for a device was suggested by the health professional as being necessary. For most people this did not appear to cause them concern. Some did not perceive that they had an option to refuse the equipment, others believed the item was essential and therefore choice was not a consideration, while others felt unqualified to determine their needs and trusted the health workers' professional judgement.

"No, I left it to them, I did not know what to expect when I got home...I wouldn't have known what to choose - they would".

"I thought they'd know best. It suited me."

It was difficult for most participants to decide on something that was outside their normal experience.

“Don’t know [if suitable] until you try it”.

Participants were also asked about the range of alternatives presented to them and if they had any choice of the type of equipment they were to receive. Most people reported being offered no choice. This was the case even for large and expensive items that could potentially have been customised, such as electric scooters. A few people were presented with a limited range of alternatives:

“She (OT) asked me which toilet seat I wanted, the one with the legs over the toilet or the one that fits on. I had that choice.”

“The only choice was the colour of the chair!”

In the few instances when a suggested piece of equipment was rejected, an alternative had usually been offered.

The method of equipment presentation was of concern to a number of participants. They perceived that there was no consultation or discussion of alternatives or options – rather the visiting therapist stated that they must have equipment/alterations. One participant suggested that:

“Younger people (OT’s) don’t understand – they tell people what to do and they wouldn’t listen to my view.”

Participants who required mobility aids reported that they had the opportunity to trial these items before prescription, but the option to trial other types of equipment varied. There was no evidence of the opportunity for extended trial of equipment either before discharge from hospital or once at home. For example, people may have ‘tried’ an armchair by sitting in it to check the correct seat height, however, they frequently did not have the opportunity to sit in it for a prolonged period of time to ascertain comfort and suitability. Hence, people were making the decision to accept a particular piece of equipment based only on the therapist’s recommendation, not direct personal experience.

Education on use of assistive devices

The level of instruction on the features and use of assistive devices was an area of interest to the researchers. None of the participants recalled being provided with written information about the devices.

“No, none at all.”

“The only instructions I got was by mouth and I put it in my brainbox.”

However, approximately half of all participants stated that they had received verbal instruction or demonstration on the use of their equipment. It was interesting to note that trialing equipment under supervision of a health professional did not appear to be interpreted by participants as ‘education’ or ‘instruction’. For example, most clients reported trialing their mobility aid before receiving it, but only 3 stated they had received instruction in its use.

In general, the issue of education and instruction did not appear to be of great concern to the participants. They expressed the opinion that the use of many of the pieces of equipment was self-evident and therefore believed that specific instruction was not necessary, as illustrated in the following examples:

“I did not feel a need [for instruction] anyway.”

“You just work it out yourself.”

“It is obvious what you do with the equipment.”

Follow-up

The majority of people stated that they had received no specific follow-up to check on their assistive devices since receiving them:

“No, no-one, not to check the equipment.”

Just under half of all people thought that follow-up would be of use, mainly to check on the condition of the equipment rather than on its continued suitability. Some people reported that they still had regular contact with a health care service and that this could provide a mechanism for follow-up, if required. Most participants would have appreciated follow-up to enquire about their general condition and health status – not specifically in relation to their assistive devices. Even the offer of follow-up was appreciated:

“It was wonderful to think they came out to see how I was coping. When I got home I got a bit paranoid about going out and he (OT) came to see if I was coping all right. He built up my confidence.”

Return of assistive devices

Most people were happy to return assistive devices if they no longer required them, but there was very limited knowledge about the mechanism for returning equipment. There was also some confusion as to whether participants actually owned the equipment, which further complicated the situation. Most people assumed that if equipment was to be returned they could ring a hospital or health care facility to arrange collection. Most were unaware that it was not a common practice for facilities to collect equipment:

“They said to me – ‘when you’ve finished with it, we take it back’ - I didn’t think how.”

“Where do we return it to, back here [hospital] again?”

“No. I wasn’t told. When I’ve finished with it I just presume I’ve got to take it back.”

Some participants reported that possession of equipment – even if it was not currently in use – provided a sense of security ensuring that they had ready access to it if required in the future:

“You may not need to use them [assistive devices] all the time, but later on like, I’ll get the use of them. There will come a time when I’ll probably need them again.”

Re-use of assistive devices

Participants were also asked their thoughts on receiving previously used equipment. All but one person was happy to receive re-issued items. The main reservation raised was about the cleanliness of items, particularly toilet aids. Generally, people assumed that re-issued items provided by a health service would be properly cleaned, sterilised, in good repair and checked for safety. The following is an interaction between two participants in one of the focus groups, which illustrates the general stance:

Mrs X: “You’ve got to have it whether it is old or new.”

Mrs Y: “The hospital, when they get them back, they sterilise them. What harm is there in me taking it from you, or you taking it from me? No harm.”

Mrs X: “That’s false pride.”

Reasons for non use/discontinued use of assistive devices

Participants were asked whether they had any pieces of equipment that they had never used, had stopped using or had returned or passed on to someone else. They were also asked to identify the items and explain why they had not used them. Only one of the fifteen home based interview participants reported still using all of the equipment with which they had been provided. The remaining fourteen participants had discontinued use of at least one item. A variety of reasons were given for current non-use. The major reason related to a change in the participant’s condition since provision of the items – either an improvement or deterioration. Other reasons reported included: advised not to use; obtained a better, more comfortable device; never needed it; or the item was found to be unsuitable. There was no particular pattern to the types of assistive devices no longer used, which ranged from small personal aids through to large mobility and bathroom devices.

Acceptance of equipment

Only one participant described being concerned about how people would view her and described an occasion where she hid her walking aid under her clothing until she had got past the neighbours. However, most had come to terms with their impairments and disabilities and perceived the equipment as a means of minimising the handicap they experienced, even though they would prefer not to use it:

“It’s a case of have to, but it can be annoying.”

“They’re not easy to accept but once you have accepted them (aids) they make life easier ... I try to think of things I can do rather than disabilities.”

Most participants were very positive about their assistive devices, emphasising that it would greatly limit their functioning if they did not have the equipment:

General - "I couldn't do without it. I use every bit of equipment I've got."

Pick-up sticks - "Wonderful things. Little tablets you can pick off the floor."

Bedrail - "I reckon it's great. I can pull myself up. I'm happy with it."

Wheely frame with seat and tray - "It's absolutely fantastic. It turns on a threepenny bit. I can sit and do my vegies and cooking at the stove, or I can put meals on it and walk around to the TV."

Suggestions of changes to equipment provision or the service system

Overall, participants were satisfied with the services they had received. Many spoke very highly of the staff involved and the help offered. A small number of suggestions for improvement were made including more discussion with carers; provision of an information sheet on agreements and procedures for assistive devices; instructions on how to return equipment; better communication and notice of home assessments; and co-payment, instalment payment or loan systems, as alternative options for equipment provision.

Discussion

The information generated through the focus groups and the home-based interviews was similar and complementary, which supports the validity of the findings (Quine and Taylor 1998), however the emphasis was somewhat different. The interviews provided a greater opportunity to gather detailed and specific information on the types and range of devices in situ and the participant's use of these, while the focus groups provided a greater opportunity to explore system issues, such as the procedure for borrowing equipment, and general attitudes towards assistive devices.

The clinician-researchers conducting the home-based interviews judged that there was not a high level of unmet need among those visited. Although the preventative effect of equipment provision has not been proven, most participants (in both the focus groups and interviews) reported that they would have great difficulty managing at home without their assistive devices.

Most participants had first hand experience of multiple pieces of equipment and different systems of equipment provision. The clients in this study were mostly satisfied with the system of equipment provision services they had received. In addition, if still appropriate to their needs, participants were mostly continuing to use the assistive devices provided. All but one participant had discontinued use of at least one item, but most had replaced the discarded assistive device with something more appropriate to their needs, indicating that they were exchanging, rather than discarding assistive devices. Overall, there were relatively low levels of non-use of provided equipment.

Cost was an issue, but participants did not expect to obtain items completely free of charge. Instead they preferred greater flexibility in payment options and were prepared to re-use, borrow and adapt equipment. People were more likely to pay outright for small and inexpensive items than for larger equipment. It was not clear whether this was based on the judgement/preference of the client or whether this reflected the hospital policies, as therapists often feel uncomfortable charging clients for assistive devices, particularly for more expensive items.

Participants reported that there was a limited opportunity to consider or select from a range of items, with most reporting being offered only one type of any particular device. However, this was not perceived as a problem as most participants did not expect to be given a choice. Commonly, they stated that they trusted the health professionals' judgement and expertise to suggest the most suitable device. Their response could also relate to the fact that the majority of participants had not made significant financial contributions for their assistive devices and therefore had lower expectations of choice and of the system of provision. The exceptions to this were two participants who reported being given no choice or opportunity to participate in decision-making when provided with a motorised scooter or wheelchair through a government scheme. Whilst they had not discontinued use of these essential items, both were very dissatisfied, as they felt these items did not adequately meet their needs. This raises the issues of equity of provision and control of the process – where those who can afford to pay the full cost of purchase have choice and also a higher level of perceived control over their own independence and function.

Participants did not recall being provided with any written information or instructions related to their assistive devices. They also reported a relatively limited opportunity to trial equipment before accepting provision. However, the general impression was that the use of most assistive devices was self-explanatory and extensive training was not necessary. This, coupled with the stated reasons for non-use, would tend to indicate that what was perceived to be relatively limited education and training was not a major contributor to non-use of assistive devices. Written information on the maintenance and also options for return of equipment was highlighted as being potentially useful.

There were a number of methodological issues. This group had relatively high levels of disability and therefore a relatively high reliance on equipment for safe and optimal function at home, which limited their choice of whether to use or not use equipment. This was a small, convenience sample, not necessarily representative of the population. There is a possibility of selection bias: dissatisfied clients may have been more likely to refuse to participate. Severely disabled clients had difficulty in attending the focus groups – however, they were offered the opportunity for a home-based interview: so this was not a barrier to inclusion. People without fluency in English, or with significant cognitive impairment, were not included. Other potential biases include acquiescence bias (Australian Institute of Health and Welfare 1998), particularly in the focus groups and recall bias about some items of equipment, provider source etc. as most had acquired equipment over an extended period: from multiple sources.

Systems for the provision of equipment in the North Western region of metropolitan Melbourne require review and development to promote:

- consistency of provision and payment policy among service providers
- flexibility of payment options and the opportunity to borrow items for short term use to minimise rejection of items through inability to pay
- adequate education and follow-up support to clients

The analysis highlighted several aspects of equipment provision where more detailed investigation is required:

- the feasibility of systems for borrowing and recycling equipment;
- the costs and benefits of equipment provision particularly in light of the resources required to provide inpatient hospital care or other supportive services to this client group;
- the patterns of equipment use for different diagnostic groups and different stages of disease would be of interest to assist with planning of equipment provision systems;
- the equipment issuing method and/or level of therapist experience and the impact this has on the process and outcome of equipment prescription.

This was a pilot study to consider the potential for further work in this area. The findings were conclusive and suggest that a replication of this study on a larger scale with similar clients is not warranted, although small-scale studies of samples from other types of provision frameworks could be worthwhile. Also, as this study was restricted to those clients who had been issued with two or more assistive devices. An investigation of clients who did not accept equipment, or were issued with only item, may be useful.

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