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Health and Community Care Research Findings No. 5

Public attitudes to the provision of free personal care: older people's focus group research

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This research, which was commissioned to inform the deliberations of the Care Development Group, explores the views of specific groups of older people regarding services and the provision of a free personal care system for older people in Scotland.

Main Findings

- Participants reported that it was important to them that the service they received offered continuity and was responsive to their needs. For people in the community the home help service and its ability to meet their needs was a key concern.
- Receiving free services did not appear to be the priority for the majority of participants. Their priority was to have their care needs met irrespective of how or who paid.
- The extent to which participants felt part of, or isolated from, a 'community' was a live issue both for those in the community and for those in care homes.
- The length of time it took to get social care aids and home adaptations, and availability of transport were key issues for those participants living in the community and, in particular, for those living in rural areas.
- Participants living in the community felt that they were not aware of all the services available to them.
- Participants in both care home and community settings spoke of the benefit of, in particular, occupational therapy and physiotherapy treatments. The common theme was that these necessary services used to be provided but are no longer available.
- In relation to direct payments, participants either expressed no opinion or welcomed the idea as one that could deliver them greater control and flexibility.
- Few participants talked about the decision they had made to enter residential care in a positive and proactive way. It tended to be as a result of a crisis, or the 'solution' to a 'problem'.

Introduction

A key proposal made by The Royal Commission into Long Term Care (1999) was that free nursing and personal care should be provided in both care homes and the community. In Scotland, the Scottish Executive responded to this by stating that it would implement this recommendation in full: i.e. free nursing and personal care for all older people. The Care Development Group (CDG) was established to examine how this could be delivered, and to analyse the costs and implications of doing so. The data gathered in this study complement those from other studies seeking to elicit views from a range of older people (service users and non-users and informal carers) across different settings. It has also informed policy development and service provision in relation to free personal care for older people in Scotland.

The overall aim of the research was to explore the views of specific groups of older people regarding services and the provision of a free personal care system for older people in Scotland.

Methodology

The study was qualitative and used focus group methodology. Views were obtained from 49 service users in seven sites across Scotland. The sites comprised two day centres, one day hospital, one residential home and three nursing homes. A pilot study was carried out in a nursing home (this group are included in the main sample) to check the relevance and clarity of the question framework.

Findings

The findings are discussed in relation to the specific topics covered in the focus groups.

Participants' experiences of caring:

The extent to which participants felt part of, or isolated from, a 'community' was a live issue both for those who lived in the community and for those who lived in care homes. Those people with sensory impairments or physical disabilities, in particular, could find themselves isolated because respondents felt they do not have the help they need to be part of the community.

Many of the participants commented on the increase in the number of people with dementia who were using the service, and on the impact they believed this had on the quality of care they received. There was a view that, in care homes, staff resources tended to focus on the needs of people with dementia to the detriment of other, more able residents.

Participants reported that it was important to them that the service they received offered continuity and was responsive to their needs. For people in the community the home help service and its ability to meet their needs was a key concern. Their experiences raise the issue of whether state funded-care services necessarily mean limited flexibility and choice for service users.

Priorities for extension and improvement of services

People had very specific concerns in relation to their own unmet needs, and therefore it did not make sense for them to prioritise those things they had already identified as being important. This meant that the whole notion of prioritising in order to identify those things that should be free made little sense to them. The primary issue was the unmet need, not how it was going to be paid for.

The length of time it took to get social care aids and home adaptations, and a lack of efficient and affordable transport were key issues for those participants living in the community and, in particular, for those living in rural areas. Participants living in the community felt that they did not know of all the services available to them. Both those in care home and those in community settings spoke of the benefit of, in particular occupational therapy and physiotherapy treatments. The common theme was that these necessary services used to be provided but are no longer available.

Universal versus selective provision

Receiving free services did not appear to be the priority for the majority of participants. Their priority was to have their care needs met irrespective of how or who paid.

Where people expressed an opinion, these fell into two camps. There were those who felt that personal care should be free because they had paid for it already through national insurance and taxation. There were also those who said they were happy to pay or to contribute to the cost of care. In fact some insisted that services should be means tested.

In relation to direct payments, participants either expressed no opinion or welcomed the idea as one that could deliver them greater control and flexibility. Those who expressed no opinion may have done so because direct payments didn't appear relevant to them, or they had more pressing concerns with quality of service. The concept was new to them and needed clarification. Some of those who were positive about the idea felt that a voucher scheme might allow them to choose different services than were currently available to meet their needs, such as a befriending or housework service.

The availability of home-based and institutional care options

Few participants talked about the decision they had made to enter residential care in a positive and proactive way. It tended to be as a result of a crisis, or the 'solution' to a 'problem'. Most participants in care homes identified a crisis in home-based care or a concern not to be a burden to family, as the reason why they made the decision to enter residential care. Many said that they simply got to the point where they felt unsafe living at home. They appeared to take the view that this decision was inevitable – the time came – and nothing much could have been done to prevent it.

Planning for the future

Perhaps unsurprisingly, it appeared to be those participants living in the community, rather than those living in care homes, who were concerned about their future care. They were anticipating a time when they would, very likely, have to make the decision to move into residential care while what they wanted was to remain living in their own home.

For those who had already experienced this transition the future had a different meaning: it was about getting day-to-day care needs met and finding pleasure in daily events or activities (e.g. having a bath, watching TV in your room at the end of the day, reading or story tapes).

Conclusion

For the majority of participants in the study, obtaining additional services provided by the state (rather than being means-tested) did not appear to be of great concern. Their concern was to have their care needs met irrespective of how or who paid. They emphasised the availability and quality of services (e.g. continuity of care, responsiveness of services to their individual and changing needs, and reliability of services) as important to them.

Participants did identify care needs that correspond to those included under the umbrella of 'personal care' as defined by the Royal Commission for Long Term Care (1999). However, there was an array of needs identified that fell outside that definition. Many of these were considered by the participants to be essential to their quality of life: for example, access to efficient transport, access to paramedical services, provision of housework services and, particularly for those living in rural areas, home adaptations.

People had very specific concerns in relation to their own unmet needs, ranging from clearing snow from their paths to emptying catheter bags. It did not, therefore, make sense for them to prioritise those things that they had already identified as being important. This meant that in this study, asking participants to prioritise in order to identify those things that should be free was of little relevance to them. Initiating a change whereby the state provides more services does not address important issues related to the quality of service provision.

In this study, participants living in the community described how, in many cases, the home-help system did not meet their needs and was inflexible. For example, hanging curtains, scrubbing bathroom floors, changing light bulbs and providing company were not activities that a home help could provide. There were other instances where the lack of continuity in community-based care prompted the individual's decision to move into residential care.

How services prioritise needs does not necessarily reflect the priorities of the individuals who receive those services. This gap in understanding between providers and recipients of care services is well-documented. In order to ensure that service provision

is responsive to the needs of individuals, a holistic and multidisciplinary approach to assessment must be developed. Such an assessment is underpinned by a philosophy that places the user's perspective at the heart of service delivery. To categorise the care needs of older people as 'nursing care', 'personal care' and 'living care' and to perceive those needs in terms of tasks to be carried out by particular groups of health and social care workers, does not support the holistic philosophy. What was evident from the participants in this study was their difficulty in actually articulating current and future care needs. More innovative methodologies that reach out to hear the voices of older people, including those with dementia, need to be considered if eliciting users' views is to become a reality.

Furthermore, people working with the older person to help them to identify their needs experience specific challenges, that require highly skilled and time-consuming activity. It is also important to note that older people have individual needs, and to divide these into rigid categories, without considering them

in combination and in an appropriate setting, is an artificial exercise. There is scope for considering a 'generic' worker who could assess individuals' needs and act as a conduit between those needs and the services that could meet them. This worker could facilitate a more transparent care system where individuals would understand what support is available and the criteria for accessing it.

This study has highlighted key issues in relation to the way that older people experience care services and how these impact on free 'personal care'. The findings corroborate a substantial body of literature looking at the needs of older people and service provision. Whilst it was important to elicit views of older people resident in Scotland in light of the proposed policy changes which will differ from those elsewhere in the UK, no new themes emerged in relation to service provision. Given that we now have extensive evidence relating to the needs of older people, the priority must focus on encompassing these needs and views, and making them central to the implementation of future service provision.

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