Person-centred dementia services are feasible, but can they be sustained?

J. R. F. Gladman1, R. G. Jones2, K. Radford1, E. Walker3, I. Rothera3

1Division of Rehabilitation and Ageing, B Floor Medical School, Queen’s Medical Centre, Nottingham, NG7 2UH, UK
2Division of Psychiatry, A Floor South Block, Queen’s Medical Centre, Nottingham, NG7 2UH, UK
3Duncan Macmillan House, Porchester Road, Mapperley, Nottingham, NG3 6AA, UK

Address correspondence to: J. R. F. Gladman. Email: john.gladman@nottingham.ac.uk

Abstract

Background: we evaluated a specialist community-based dementia service to establish whether high quality care was being delivered and the conditions for doing so. The service was in an urban part of Rushcliffe Primary Care Trust, Nottinghamshire, United Kingdom. The service comprised an assessment team of an occupational therapist, a community psychiatric nurse and a community care officer, supported by 235 h per week of care delivered by a team of specially trained community care workers.

Methods: a qualitative study was performed using non-participant observation, semi-structured interviews and focus groups, and analysed using a thematic framework approach. There were 2 focus groups involving staff, 11 interviews of staff and stakeholders, and interviews of 15 carers of people with dementia.

Results: the care provided was appreciated by carers, and the service was approved by staff and stakeholders. Care was delivered using a rehabilitative style that aimed to maintain personhood, rather than to promote independence. Clients were usually referred with the object of preventing unwanted admission to institutional care but, over time, moving into an institution ceased to be a uniformly undesirable outcome. The service’s resources were reduced during the evaluation period, in part to meet mental health needs in intermediate care services.

Conclusions: an appropriately resourced and constructed specialist service using an adaptive rehabilitation approach aimed at maintaining personhood can deliver good individualised care to people with dementia, but specific and appropriate commissioning for these services is needed to nurture them.

Keywords: dementia, service evaluation, rehabilitation, elderly

Introduction

The care of people with dementia is one of the greatest challenges facing modern societies because of the increasing numbers of people with the condition and the nature of the suffering and distress associated with it. Services provided for people with dementia have been criticised in reports such as the UK Audit Commission’s ‘Forget-Me-Not’ [1] which found them inflexible rather than person-centred, with poor integration of health and social services. The UK National Service Framework for Older People identified one of its ‘standards’ as ‘mental health in older people’ and called for services that are ‘comprehensive, multidisciplinary, accessible, responsive, individualised, accountable and systematic’ [2].

Specialist services for people with dementia have been developed in recent years in response to these requirements. One example was the Daisy Chain dementia support service, set up in an urban part (West Bridgford, population approximately 36,000) of Rushcliffe Primary Care Trust, Nottinghamshire, United Kingdom. The service comprised an assessment team of an occupational therapist (who was also the service co-ordinator), a community psychiatric nurse and a community care officer, supported by 235 h per week of care delivered by a team of specially trained community care workers.
disturbance, and lack of self-care including inadequate examples of crises when they were referred to the Daisy Chain service. Provisions such as the Nottingham Daisy Chain service are effective or about the conditions for effectiveness. The opportunity to evaluate this service arose when the service co-ordinator approached the rest of the research team, who had no clinical relationship with the service, asking for an external independent evaluation. We evaluated the Daisy Chain service using qualitative techniques aimed at illuminating the relationship between aspects of structure and process upon outcome.

Methods

Data were collected over 18 months from February 2003. Local research committee approval was granted.

Two researchers observed the Daisy Chain team at work, its meetings, documentation and database. Field notes were kept and compared between researchers.

Two focus groups were arranged where Daisy Chain home care staff described their practice and their views of its effectiveness. Findings from the first focus group were explored in the second focus group. Six local General Practitioners in the locality, the old age psychiatrist for the sector, NHS patient advocates, the manager, representatives of the Carers’ Federation, and a representative of the Alzheimer’s Society were interviewed. These interviewees were asked to describe their roles and comment upon the effectiveness of the Daisy Chain service. The project co-ordinator was interviewed, and asked to discuss the areas covered in the staff focus groups.

We initially aimed to study and interview two cohorts of 15 users of the service, the contents of the second set of interviews being informed by the findings from the first. We also examined and summarised the clinical notes of each participant with dementia to aid the interpretation of the interviews.

Permission to approach typical clients of the service was sought via the project co-ordinator, who discussed the matter with patients and their carers.

All 15 cases had been living alone and had been at a point of crisis when they were referred to the Daisy Chain service. Examples of crises included wandering or behavioural disturbance, and lack of self-care including inadequate eating, drinking or personal hygiene, or suspected alcohol abuse, each of which required consideration of the need for institutional care. These problems were often associated with the person with dementia being unwilling to accept care. Permission to approach the patient directly for an interview was not given in any of the cases, but the carer agreed to be interviewed in each case. The carers were children, nephews or nieces, or family friends. Interviews were semi-structured: respondents were asked to describe the health and welfare issues arising with the patient, describe the involvement of the Daisy Chain service, and comment upon its value.

While analysing the first set of interviews, we became aware that several of the patients had moved from their home into long-term care. In view of the fact that reducing institutionalisation was a core objective of the service, we chose in our second set of interviews to interview as many of the first cohort as possible instead of a new cohort. Fifteen interviews were undertaken in the first set of interviews, and repeat interviews were performed in seven of these (seven others declined and one was in long-term care at the first interview).

All field notes, focus groups and interviews were tape recorded and transcribed. Consent was obtained for all interviews. Assent was obtained to examine the clients’ medical records.

The analysis used a framework approach [4] in which a framework of themes was identified from all available data through a process which had coded, indexed, charted, mapped, interpreted and, where necessary, re-coded them. Three researchers (JG, EW, KR) discussed the emerging themes.

Results

Outcomes

From carers’ perspectives, good outcomes were characterised by the person with dementia coming not only to accept care, but also to enjoy doing so. This greatly reduced the stress experienced by carers. Carers deemed the service good because the care workers were kind, showed patience and understanding, and enjoyed the company of the person with dementia. Good communication with carers was reassuring and another mark of success. A well-used communication book in the patient’s home for staff and carers was cited as an example of this. Carers contrasted their experiences of the Daisy Chain service with those of previous care services, where specific care tasks were undertaken in fixed periods of time and where little pleasure appeared to be drawn from doing so. Table 1 shows the range of carers’ quotes illustrating the overall impression of the service, and its benefit to both the person with dementia and the carer.

Staff of the service independently expressed similar views, also drawing comparisons from their previous experiences in other services providing care for people with dementia. Other professionals such as GPs and patient advocates expressed positive views: GPs reported being less troubled by patients receiving the service than hitherto, and advocates felt that
the style of care was more appropriate to the patients’ needs than usual (non-specialist) care.

Not all views about clinical effects were positive: one carer at outset, two carers at follow-up and the old age psychiatrist expressed differences of opinion about how long patients should be maintained at home rather than in an institution, with these respondents indicating that the service persevered in avoiding institutionalisation too long. Figure 1 provides positive and negative illustrative case vignettes.

**Style of care**

The style of care, as ascertained from all our sources, was articulated by the project leader, an occupational therapist. She referred to a ‘rehabilitative approach’. This meant a careful assessment of a client’s ‘whole day and how it is structured’ and ‘the way a person functions within his/her life’. She proposed that this assessment process took up to 12 weeks during which a bespoke package of care was established. Examples of care included improving compliance with medication (e.g. ensuring that eye drops were given), taking a person to the doctor, or taking the client for a walk by the riverside, as had been their previous habit. Aids and appliances were provided (e.g. bath aids, a stool for kitchen use or a commode). Illustrative Case 1 in Figure 1 provides another example of intervention. Formal, restorative physical or cognitive exercises aimed at impairments were not used.

Liaison with other agencies was common, including going to the district nursing service for promoting continence, and to the old age psychiatry day hospital. Episodes of care were often daily or several times daily. The assessment team communicated frequently with the home care worker to ensure that the reason for the support activity was understood and that the home care worker had the necessary time, skill and resources to undertake it.

The special care workers were in little doubt about what enabled them to achieve these outcomes. Special training was required, in particular, to understand behaviour in dementia, welfare rights, human rights, suicide risk, and compliance with medication. They also needed the time to act outside their traditional task-focused and time-limited roles. Providing emotional support, where necessary, was an intervention that was seen as part of good-quality care: in their previous experience in ordinary services, visits were justified only to perform a specific task such as helping with washing or dressing. To act in this new way, they needed supportive contact with senior professional staff. They also explicitly recognised a shared autonomy-respecting ethos (making specific reference to education about the concept of ‘personhood’) that influenced their actions.

The aim of this rehabilitation intervention was not the promotion of independence in task performance, but to

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**Table 1. Quotes illustrating themes about the efficacy of the service from interviews of carers of people with dementia**

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<thead>
<tr>
<th>General impressions</th>
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<tbody>
<tr>
<td>Son of Case 1, lady with Alzheimer’s with whom he lived. ‘It is an excellent service on the whole. I hope everyone gets the same service who find themselves in a similar situation.’</td>
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<td>Daughter of Case 11, lady with Alzheimer’s who lived alone. ‘I think it is an excellent organisation, I think they do the job that they are asked to do and Mother is happy and I’m happy.’</td>
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<td>Nature of benefits to person with dementia and the informant (carer)</td>
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<td>Son of Case 1, lady with Alzheimer’s with whom he lived. ‘They are very good. They try to make up for the fact that she no longer had the car, she was still able to move around, you know, mobile so they used to take her out, help her with her medication. I think they called every day and did something different every day. You see, Mum used to be a hairdresser, she loved being with people, still does, you know she’s chatty, chatty, likes hustle and bustle.’</td>
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<td>Niece of Case 7, lady with Alzheimer’s who lived alone. ‘She liked them all. She enjoyed their company.’</td>
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<td>Daughter of Case 11, lady with Alzheimer’s living alone. ‘Motivation is the biggest thing. She hadn’t been in the bath or had a shower or anything for, I would think, years rather than months. I knew that Mother would feel uncomfortable if I was to say “come on, strip off I will help you wash”. She would not want that. Although she felt it was quite difficult at first she is quite happy for the carers to do that.’</td>
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<td>Daughter of Case 13, lady with Alzheimer’s who lived alone. ‘Without Daisy Chain I think I would have gone under a long time ago and then what would have happened to Mum?’</td>
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<td>Daughter of Case 14, lady with Alzheimer’s who lived alone. ‘She’s cleaner and the flat is cleaner too. That’s so important. You don’t like to think of your Mum being dirty and smelly, do you?’</td>
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**Explaining and justifying success**

| Nature of benefits to person with dementia and the informant (carer) | | | |
| Niece of Case 7, lady with Alzheimer’s who lived alone. ‘After the assessment, the carers started going to see Aunty. They were fantastic. It was a weight off my mind. They were efficient and professional but gave Auntie all the time she needed. They visited three times a day to keep an eye on Auntie’s mental health and diet and tablets they were concerned that she ate and drank properly.’ | | | |
| Nephew of Case 8, who lived in another city some distance from his aunt who had Alzheimer’s and lived alone. ‘She wants to stay at home. They make that possible. She wasn’t looking after herself properly and now she’s doing more. You know, she’s better. They spend time with her, you see. They don’t rush her. They have increased her visits from one to three a day. It’s been great . . . I found it difficult when she became incontinent. I can’t talk to mum about this. She used to have carers from social services going in 1 h a day. This wasn’t working. Well it wouldn’t, would it? Mum needed more than that. They tried using bigger pads for her “problem”. They just weren’t able to give her any more time.’ | | | |
| Daughter of Case 13, lady with Alzheimer’s who lived alone. ‘They’re very patient, always give Mum time, don’t rush her, reassure her and all that. I like the way you always know what’s happening.’ | | | |
| Daughter of Case 14, lady with Alzheimer’s who lived alone. ‘They’re much more patient than me. Mum gets upset sometimes which upsets me and then things seem to get really tense and things start to go wrong. She gets upset and then I get upset and that’s how it goes on. I don’t know how to deal with her sometimes, she just goes on and on and it grinds me down.’ | | | |
Avoiding institutionalisation

In the service documentation and in focus group discussions, the prevention of unwanted institutionalisation was acknowledged as one of the Daisy Chain service’s core objectives. At the point of referral, most carers wanted the person for whom they cared to remain in their own homes.

However, avoiding institutionalisation per se was not the objective, as in illustrative Case vignette 2 (Figure 1). Table 2 gives examples of interviewee quotes illustrating the complex and changing views on the desirability of institutional care. The reason for the change in view over time appeared to be that as time went by the awareness of the person with dementia deteriorated to the extent that they no longer seemed to take overall pleasure from being at home or when the risks of being alone were unacceptable. Avoiding institutionalisation when unwanted was an objective at one point in time, but facilitating a smooth move into an institution could be an objective later on in the same person’s care.

Management and policy

The project co-ordinator convened the bi-monthly Daisy Chain steering group meetings. The local commissioners sought evidence of activity and effectiveness, and discussed the service in terms of the implementation of higher level policy issues.

There was a lack of common understanding between the clinicians and commissioners at steering group meetings. The health and social services funding for this service had been allocated on the basis that it was supporting the development of intermediate care services, for which explicit targets had been set for both organisations. The justification for doing so was that the Daisy Chain service might prevent hospitalisation or institutionalisation. However, commissioning health and social services staff were increasingly vexed that referrals to Daisy Chain were not being accepted rapidly, e.g. from hospitals, and neither were clients being discharged. The rehabilitation approach applied by the Daisy Chain team appeared to be misunderstood by commissioners familiar with intermediate care services. Hearing the word ‘rehabilitation’, they expected to see evidence of the restoration of enable the person to live as normal a lifestyle to their chosen one as possible, by the tailored provision of support.

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Table 2. Quotes illustrating attitudes of carers to institutional care

- Daughter of Case 2, lady with vascular dementia who had been supported by Daisy Chain for a year at the first interview but had recently moved to a residential home. ‘We pay £1,600 a month and it’s worth every penny.’
- Family friend of Case 4, bereaved man with alcohol abuse and Alzheimer’s, who had lived alone, about the change in him when admitted to a residential home. ‘He’s really happy. We’re happy. He has his own room but doesn’t have to worry about bills and eating. It’s all done for him. We see him regular and it suits us.’
- Nephew of Case 6, a lady with Alzheimer’s disease who lived alone, was happily supported by Daisy Chain at the first interview but who had moved to a care home at the second interview, and had then died. ‘She lived it and it became her home’
- Nephew of Case 8, second interview, at which point his aunt had moved to a residential home, and then died a few weeks later. ‘It was the right thing to do. She wasn’t alone when she died. That’s important to me. Long-term care is OK when the time is right. It would not have been right a couple of years ago, but was then.’
- Second interview of daughter of Case 9, lady with Alzheimer’s who had lived alone at the first interview. ‘The time was right . . . without Daisy Chain [names of personnel], . . . this would have happened a long time ago’
- Daughter of Case 10, lady with Alzheimer’s who lived alone, who remained at home on second interview one year later. ‘The House Manager [warden] suggested I look for somewhere else [for the person with dementia to live]. A registered home. However, the Daisy Chain view was very different.’
- Daughter of Case 11, lady with Alzheimer’s living alone. ‘I would like to think she can stay there [at home] until she becomes a danger to herself’
- Daughter of Case 13, lady with Alzheimer’s who lived alone. ‘I want Mum to remain at home for as long as possible and will try and do everything in my power to make sure that happens. I don’t want to live with her in a home, it would break her heart, I can’t do that to her’
- At the first interview with the daughter of Case 14, lady with Alzheimer’s who lived alone. ‘I didn’t, and don’t want, Mum to go into a home, she’d hate it. Daisy Chain means she can manage to stay at home. It’s all a bit fragile though.’ At the second interview, Case 14 had died while awaiting placement in a nursing home. Referring to Daisy Chain’s reluctance to move her mother to a nursing home the daughter said she was: ‘Let down by them in some ways . . .’
Person-centred dementia services

We found that this specialist dementia service delivered a different style of care from standard service provision to people with dementia. Instead of impersonal, task-focussed and time-limited interventions, this dementia support service provided a personalised and flexible package of care, which involved pleasurable social interaction. It appeared to deliver a service that was in accord with modern advice about good dementia services. This care was highly appreciated and preferred by both carers and staff. The specialist service dealt with needs that the usual service was unable to meet, most of its referrals being clients in crisis despite support from such services. Clearly, specialist dementia services are feasible. The successful delivery of this style of care required the creation of a health and social services team, with a skilled and knowledgeable leader, an increase in resource levels, and improved staff education and training.

Despite the fact that our service user sample was small, our findings are unlikely to be unrepresentative since the reports from service users accorded with observations from service personnel and other professional and interested parties. A drawback of this study is that we did not obtain data directly from people with dementia themselves. We think it likely, but cannot be certain, that the improved quality of life and care observed, and reported by carers and staff, would have been reported by the people with dementia themselves, if we had been able to ask them. We were aware that interviewing people with dementia themselves is possible and valuable, particularly, in the early stages of the condition [5, 6] and indeed we planned to do so if possible. However, we respected the views of the clinicians who gave us access to our interviewees that many of the people with dementia in the service were either too impaired or disturbed to be interviewed, or that their carers were reluctant to assent to the interview process fearing that it might upset the person with dementia. It follows that a potential bias of the study is that the project co-ordinator who negotiated access to interviewees could have influenced the likely responses we obtained. Being aware of this we specifically requested cases where outcome was known to be less than ideal and all analyses were undertaken independently of the project co-ordinator.

We studied a new service, which may have been staffed by unusually motivated or skilled personnel. This does not mean that the success observed here cannot be replicated elsewhere, nor maintained. However, ensuring good teamwork and ongoing team education seem important for achieving this. Fortunately, working in this way increases job satisfaction, and therefore may be sustainable in individuals and stabilises the workforce [7]. The service we studied was small, but the sort of clients it dealt with and the way it did so are not likely to be unique to this geography. Overall, our findings, that high quality community dementia care can be delivered, are likely to be replicable in other settings where such specialist support services for dementia do not exist and where meagre health and social service provision lacks co-ordination. Our findings are similar to another study of a similar small service [8].

We have shown that high quality home support for people with dementia can be delivered, but we also suggest that examining their cost-efficacy using quantitative designs may not be easy because of the difficulties of identifying and measuring the appropriate meaningful outcomes. Measuring quality of life in dementia is problematic [9]. Institutionalisation rates or levels of dependence in activities of daily living do not seem adequate indicators of the value of the outcomes. Valid and routinely usable quantitative measures of personhood are required.

The importance of rehabilitation is now widely recognised in health service policy, but ambiguities in the understanding of this term may be partly responsible for the decisions that led to the reduction in the capacity of this service. We suggest that the staff of this dementia support service delivered an adaptive style of rehabilitation but that the commissioners of the service assumed a restorative model of rehabilitation [10]. Adaptive rehabilitation aims, in the terms of the World Health Organisation’s International Classification of Functioning and Health [11], to optimise role performance or participation—in the case of people with dementia to preserve their social integrity and value. The term ‘personhood’ [12] refers to a similar concept. Interventions required to do this include those that maintain co-operation from others (such as the provision of respite
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to support key carers), or provide assistance (such as home care workers) or make task performance easier (such as aids or adaptations). Restorative rehabilitation aims to promote recovery, typically of impairments or activities. Adaptive rehabilitation is suitable for progressive conditions, where attempts to achieve independence in task performance are likely to be ineffective or rapidly lost. The adaptive rehabilitation approach typically requires long-term contact yet restorative rehabilitation, as assumed in intermediate care, demands a short-term approach. The service staff and the commissioners may have been at cross-purposes because of their understanding of rehabilitation.

The UK National Service Framework for Older People [2] supports the development of good dementia services through standards related to patient centred care and mental health services. However, explicit targets were only set in the standard for the development of intermediate care services, presumably as intermediate care was expected to deliver important benefits with pressures on NHS hospital beds. This study suggests that, in such a target policy climate, while services may flourish where appropriate targets encourage them to do so, services without appropriate targets, such as important support services for people with dementia, may wither. This study suggests that ill-judged pursuit of target driven policy can therefore damage high standard person-centred services, presumably to the detriment of quality of life for patients and carers.

Key points
- High quality dementia care in the community can be delivered using a skilled, dedicated dementia team.
- High quality dementia care uses an adaptive rehabilitation approach aimed at maintaining personhood and participation rather than independence.
- Preferences for and against moving into an institution change over time and institutionalisation rates are not good targets for dementia services or indicators of their success.
- Appropriate health service targets are needed to sustain new dementia services.

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Conflicts of interests

None.

References


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