

**Dementia Care in England: Focus Groups with
Older People, Carers and Professional Staff**

RightTimePlaceCare WP2

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DEMENTIA CARE IN ENGLAND: FOCUS GROUPS WITH OLDER PEOPLE, CARERS AND PROFESSIONAL STAFF

RightTimePlaceCare WP2

INTRODUCTION

This paper is part of the European Union funded study *RightTimePlaceCare* which examines transitions and balance of care in dementia care in 8 European countries. It is part of work package two of the study which examines the structures and processes of service delivery in each country. The paper summarises the findings from the focus groups conducted with older people, carers and providers of care for older people with dementia. There were five focus groups undertaken during December and January 2011-12, three involving older people and carers and two involving professional staff involved in mental health care.

METHOD

Participants - Carers and patients

Participants for the carer/patient groups were recruited using a number of sources. The names and details of carer group organizers were gathered using professional staff from our community organizations, and also through the websites of carer groups in the local area. In order to reduce the likelihood of drop-outs to the focus groups the project team offered to carry out the meetings at the carer group premises. Nevertheless, in one locality the contact person was afraid that few people may attend the group, due to poor weather conditions and the time of year, so as a result a third group was arranged in order to maximize numbers. However, subsequently all three groups were well attended. Each of the groups was run at the carer group premises, two of them prior to the groups' usual monthly meeting.

Group A was attended by 8 members including two 'silent' members, both people with dementia who were unable to participate in the discussion. There were four persons with dementia and four carers: two spouses and two daughters. In Group B, 9 members attended with one 'silent' member with dementia. There were 7 people with dementia and two carers, both spouses. The group also included two 'buddies', formal carers accompanying the persons with dementia. In Group C, 10 members and two support workers attended. This group was purely carers, all of whom were spouses. Some were ex-carers whose relatives had recently died, but they were still supported by the carer group. These are summarised in Table 1.

Table 1: Carer/patient participant details

Participants	Age range	Gender	Duration of memory problems	Living situation	Type of support received
Group A (n=8): PwD Carers	58-94 yrs 71-94 yrs 58-73 yrs	3m 5f 2m 2f 1m 3f	18 mnths – 7 yrs	8 At home 1 Care home	Overall: 8 support group 1 home care 1 day care 7 informal care
Group B (n=9): PwD Carers	54-80 yrs 54-80 yrs 71-74 yrs	5m 4f 4m 3f 1m 1f	12 mnths – 8/9 yrs	9 At home	Overall: 9 support group 9 informal care
Group C (n=10): Carers PwD (not present)	64-87 yrs 65-87 yrs	2m 8f (8m 2f)	2 yrs – 10 yrs	6 At home 4 Care home	Overall: 10 support group 3 day care 2 respite care 1 Relative's Assoc 1 home care 1 home nursing 8 informal care
Total (A, B, C) PwD Carers	54-94 yrs 54- 94 yrs 58- 87 yrs	10m 17f	12 mnths- 10yrs	23 At home 5 Care home	27 support group 4 day care 2 home care 1 Relatives' Assoc 1 home nursing 24 informal care

There were too many participants to detail individually in Table 1. The table illustrates the age range, gender, duration of memory problems, living situation, and type of support received for the group as a whole, and for PwD and carers separately where appropriate. The mean age of PwD in Group A was 79 years, and 64 yrs in Group B (including early-onset patients). There were no people with dementia in focus Group C but the average age of those being cared for was 78.6 years. Carer average age in each group was respectively: 65.5 years; 72.5 years; and 75.2 years. The mean age of the 11 PwD who attended the groups was 69.5 years, and the mean age of the 16 carers attending the groups was 72.4 years. In total there were 10 males and 17 females. The duration of memory problems in the PwD ranged from 12 months to 10 years. Other than attendance at the carer support groups, few carers of PwD received statutory services. Informal care from other family members was received by 24 of the 27 participants.

Each focus group was attended by a facilitator and an observer who took notes and details of the seating plan for participants. Refreshments were provided by the project team during the focus group. Two of the three groups were carried out over a 2 hour slot, with the third conducted over 1 hours 15 minutes. Prior to the focus group discussion, participants were given Information sheets and asked to read and to sign consent forms, or the carers on behalf of PwD who did not have capacity. Everybody completed a demographic sheet providing background details of the participant and their cared-for relative. All participants were happy to complete these. Prior to commencing the meeting, participants were informed of the expected length of the focus group, around one hour, and that the meeting would be recorded, to which there were no objections. Two digital recorders were used in each group. The facilitators gave a short introduction to describe the purpose of the focus group to participants. Following the focus group, carers or carer-patient dyads were provided with shopping vouchers to the sum of £20 (€24) in recognition of their contribution.

Participants - professionals

The participants for the two staff focus groups were recruited via invitation through the NHS Care Trust with whom the project team was already working. Managers in three localities were approached, and the two who were able to set up meetings with the project team and members of staff in their locality within the shortest period of time were invited to participate. The managers agreed to invite a range of professional staff within their multidisciplinary teams. The same procedures used for the carer groups were undertaken for the professional groups, in that focus groups were run at the working premises of the two localities involved. Both groups were carried out during the lunchtime period, to encourage as many staff members as possible to attend.

Group D was attended by 13 members of staff. A consultant in old age psychiatry and a psychologist were invited to the group but neither was able to attend on the day. All participants were based in the community. Group E was attended by 10 members of staff. Some participants were based in the community whilst others were hospital-based. These are shown in Table 2.

Table 2: Professional staff participant details

Participants	Workplace	Profession	Experience in dementia care
Group D	Community	2 Team managers 4 Social workers 1 Support worker 2 Student nurses 2 Carer services officers 2 Community psychiatric nurses	Over 25 years Between 8yrs and 25 yrs 25 years First placements in dementia care Between 20yrs and 32 years Between 20yrs and 25years
Group E	Both Hospital Both Community Community	1 Service manager 1 Old age psychiatrist 4 Nurses 3 Community psychiatric nurses 1 Assistant practitioner (carer support worker)	25 years 36 years Between 15yrs and 17 years Between 12yrs and 20 years 6 years

Table 2 illustrates the workplace setting, professions and experience of the professional staff attending the two focus groups. Both groups represented staff who worked with the carers of older people with dementia. It was not possible to include representatives from home care agencies or care homes in the required time as their availability was constrained. The majority of participants had several years experience of working with older people with dementia. Experience ranged from first placements within dementia care for two student nurses, to over 25 years experience for managers, community practitioners and an old age psychiatrist.

Both focus groups for professionals were attended by a facilitator and an observer who took notes and details of the seating plan for participants. Sandwiches and refreshments were provided by the project team since the focus groups were completed during lunchtime. Both groups ran for a period of just over one hour. Similar to the carer/patient focus group discussions, participants were given Information sheets and asked to read and to sign consent forms. Again, all participants were happy to complete these. Prior to commencing the meeting, staff participants were informed of the expected length of the focus group, and that the meeting would be recorded, to which there were no objections. Two digital recorders were used for both groups. The facilitator gave a short introduction to provide brief details about the project as a whole, and then described the purpose of the focus group to participants. The numbers of NHS staff attendees were recorded so that the UK's NIHR CLRN (National Institute for Health Research Comprehensive Local Research Network), which provides support for clinical research, could reimburse the NHS Trust for the time provided by participating staff.

Activity

In total, five focus groups were undertaken; two with professional staff and three with carers/patients. Each of the carer/patient focus groups were undertaken in three different localities and the professional staff focus groups in two of these three localities.

The main problems encountered was the difficulty in accessing older people with dementia with regards their availability to attend focus group meetings a long distance from their homes. To overcome this, the project team used established

support groups attended by carers and people with dementia and travelled to where the carer groups were being held. A third carer/patient group was arranged in advance to ensure a sufficient level of attendance as the first carer focus group was anticipated to be small.

Analysis

The digital recordings of each of the five focus groups were professionally transcribed. Following this, the transcripts were carefully reviewed for accuracy and missing information by one of the research team who had attended each of the focus groups, using the digital recordings. The completed and validated transcripts were read by all members of the research team using content analysis (Stevens, 1996), to summarise the findings.

FOCUS GROUPS WITH OLDER PEOPLE AND CARERS

Participants' contextual situation as described

For older people and their carers the point of access to clarification, recognition and diagnosis of the problem they were experiencing was mainly through the general practitioner as the gatekeeper to health and sometimes social care. More substantial support, such as home care and community mental health teams, was likely to be available later in the illness and often after diagnosis people were reliant on support and advice associated with the memory clinic and support groups.

Participants' description of the information and communication with professionals

It was clear that there was marked variation in diagnostic responsiveness and knowledge of dementia by GPs, who were the first port of call for older people and their carers. For some this was a positive experience:

"Well our GP was very good. When I took my husband to see the GP and on the second visit ..I was going to ask him if he could tell me what I could do, if I could go to any special service or anything like that, the memory service, and ...he was asking my husband how he was and could he remember anything now and he said, - "no it seems to be going worse", so he said, - 'I think I'll refer you to the memory service', so, you know.., I thought that was excellent, he seemed to be really on the ball but I know they're not all the same." DS230061

However, some GPs were apparently unresponsive to patterns of symptoms and were experienced as dismissive of the underlying problem of cognitive decline:

"in my case, - 'what can you expect at your age?', sort of thing." DS230060

"take a few paracetamol, you will be all right." DS230060

Clearly a great deal was contingent upon which GP the family were registered with in order to progress to effective assistance.

Another theme with respect to communication was between care agencies when for example a family moved jurisdictions. In this case they would need a reassessment of need in order to access services:

"Both of those systems, both NHS and the local authority system behind it actually work incredibly slowly. When we actually moved from A*** (town) to B*** (town), it took six months for the social worker to come out about Mum being blind. So if there's a need for improvements it's there." DS230059

Participants' description of the information and communication over the trajectory of dementia

There was considerable variation of carers' experience throughout the course of the illness. As noted earlier, there was sometimes a requirement in the early stages to be very persistent on the part of the carer in order to gain a diagnosis. Indeed,

sometimes it appeared that patients and their families could get no further than to consult general practice.

“The questions that they asked, they seemed stupid to me. I had to go twice before he referred him to the hospital. For starters, he said there was nothing wrong with him but it’s been.., it had been coming over months and probably years before he was diagnosed.” DS230061

“We didn’t get any help at all. I didn’t get sent anywhere.” DS230061

However, it appeared that where people obtained access to their local memory clinic for assessment and diagnosis that was a very positive experience.

“Well I found my Memory Clinic was very good.” DS230061

“The Memory Clinic is very good if you can get them.” DS230061

In the later stages of the condition, a number of aspects of support were valued. Carer training and support groups, often provided in the early stages, were viewed very positively in that they gave people understanding of what the diagnosis meant and a degree of preparation for coping with the condition as it progressed:

“it was quite a long information thing, learning about caring. I mean I found it at that time incredibly depressing because you were looking at varying patterns and it was all sorts of scientific things as well. One of the things that we sort of talked about over and over again was all the sort of organisations that there are out there and will provide help and I mean.., they signpost internationally there’s all sorts of things going on in the area and there are ways of being a carer where you can have support and you can organise people.” DS230060

Provision of regular reviews was experienced as a source of comfort and providing access to identifying ways of coping for carers:

“I have a review every year at [day care centre] they send for me every year you know.., and we talk about it and how they could help me you know, to cope better.., and yes, I’m quite satisfied.” DS230059

However, it appeared to be the case that generic services were less helpful than specialist services in the later stages of the condition. Thus for example, social workers who were based in non-specialist services seemed less able to be of assistance due to the marked variability of their workload:

“...everybody has had a different pathway and a different kind of a diagnosis, and the type of dementia and other factors... as J— (PwD) has outlined .. he has had a social worker in the past from older people’s services which is generic so that social worker probably had on their caseload somebody with cancer, somebody with a stroke, cardio issues.” DS230061

Participants’ description of the information and communication depending on if cared for at home or in a nursing home

In the discussion little emerged as an issue from the participants in relation to this issue.

Participants' description of collaboration with professionals

As noted earlier, regular reviews were valued by carers and carers' training programmes, delivered by professionals, were seen as very helpful as a form of planned access to services:

"carers can come to a six week session on carers information here, and those sessions for the last twelve.., thirteen years.., have been always oversubscribed...The difficulty that we have had is that we've not been able to offer a lot after that, but there's been a lot of solid information from various professionals over the six week period." DS230060

A commonly noted theme was about the degree of integration between professional groups and the need to have a more integrated service. This was expressed in terms of the need for a one stop shop or single point of access and also for better integration between different sectors of the health service:

"I mean even in the NHS.., yes it's not happening.." DS230059

"It's things like communication between GPs, everybody, Consultants, Social Workers, dementia advisors." DS230059

Participants' description of the collaboration with professionals over the trajectory of dementia

It has been already noted under discussion of communication with professionals that the experience of GPs (whether as communicators or collaborators) was variable and contingent upon the qualities, skills and interests of the individual practitioner. The experience of the initial diagnosis and advice from memory clinics was generally more positive. A common theme was the desire for a single point of access and continuing contact for families in the early stages of the illness. This amounted to a perceived need for a dementia adviser acting as an early stage case manager helping people to navigate the complex network of services:

" the dementia advisors [came] in to see me at home, then they got me my own social worker who was fantastic, absolutely through her, we got a social worker for D—(PWD) who came to our house." DS230059

"Well the carers place in B**, ... it's the first port of call I went to,they've had the dementia advisors in to talk to us. You know they get people in to talk to us." DS230059

In the later stages of the condition, when receipt of home care and in-patient admissions occurred more often, care was experienced as particularly problematic when home care and hospital staff were recruited from different countries and had some difficulties in communication. This led to problems in the quality of care:

" The ward that my husband was on for the last four years of his life, they quite often had people coming in and English wasn't their first language and the people they were talking to could not understand them and likewise I don't think that they understood much of what was being said. So...somebody could have been in quite a bit of distress and they'd try to put their point across verbally and it just wasn't being understood." DS230061

The care in hospital needed to be more individualized and responsive to the unique circumstances of people with dementia:

Respite care was seen as a very crucial service for families supporting an older person in the later stages of dementia:

“They pointed me in the direction of Crossroads as well, so for two hours, today.., so I can go to an exercise class, they come into D—(PwD) and they sit with him at home...If I didn’t have that I would be so uptight, and it’s wonderful, and then on a Tuesday when Crossroads comes in that’s another two hour slot that I can be by myself and meet friends ..” DS230059

Participants’ description of the collaboration with professionals depending on if cared for at home or in a nursing home

This issue was not addressed by the participants.

Participants’ overall reflection of care at its best versus not at its best

GP care was seen as highly variable and improvement in the early diagnosis phase was seen as very important. It appeared from the observations made by the participants at the different focus groups that support commissioned from voluntary organizations was working well although there was concern at differential access to these services since they were less available in the more socio-demographically deprived areas. Day and respite care services were particularly valued:

“...the day care, I find that a big boost for me. I started off one day a week, two days a week, three four, now five so R--’s only home two days a week. So to me yes, day care is one of the most important things.” DS230061

In-patient care was identified as needing greater responsiveness to dementia and one participant provided a simple low cost example of the benefits of this avoiding nutrition and hydration problems:

“I was allowed to stay with my husband in hospital last time he was in. I was allowed to go and stay to help him with his lunch and his dinner.” DS230061

Carers were consistently concerned about the numbers of people whom they saw and the numbers of means of entry to help and support. They identified the benefits of simplification, a single point of access and identified contact/case manager:

“I ... am bombarded by the amount of people that you see, and you don’t even know what their job role is sometimes, or what information they’ve got.” DS230059

“In the pathway to dementia what we need is a one stop place where you can talk to people about their own subject. What you need and you know with these things they change fast.” DS230061

FOCUS GROUPS WITH PROFESSIONAL STAFF

Participants contextual situation as described

Most professional staff were working in community mental health teams or were linked to these services. In general rehabilitation services were singled out for praise. Key concerns they were the lack of community physiotherapy services; the poor quality of generic home care services for the special and unique needs of people with dementia and coupled with this the need for specialist home care with a training and knowledge base appropriate for dementia care:

“...the Home Intervention Team (a service to prevent inappropriate admissions to hospital) go in for emergency situations and they are very skilled and experienced people so they will be able to deliver a high standard of care and then the (usual) carers come in and take over and the thing will just fall down because..they just don't have the skills.” DS230058

The processes employed to pursue quality of care and drive up standards, through careful monitoring of activity and prescribed targets, were strongly criticised as in fact being deleterious to quality care:

“I personally believe that at the moment we are being pushed into counting everything, so it is count, count, count and that is the focus of quality, so if you can count it, it is quality, and I don't think it is.. so we spend an awful lot of energy counting things because that seems to tick boxes...”. DS230058

“It is very much the fact that we need to return to the value being the point of contact work, to free up Nurses, qualified Nurses with the skills, knowledge and experience.. at the point of contact with patients to provide quality care, rather than the way our time is spent and the way in what we do is measured, so our job is very subjective and it is being measured by using statistical and numerical methods, ...and it is a complete waste of time..” DS230058

This can be seen as a critique of the experience of working in the environment created by the use of New Public Management approaches, and their impact on patient care.

Participants description of the information and communication from and between professionals

Although memory clinics were clearly valued by carers, it was noteworthy that due to high demands for their services, professional staff saw delays between assessment and diagnosis as being too great and leading to anxiety in pwd and their families:

“..relatives say that the gap from being told the diagnoses, to having the assessment in the clinic then going back for the diagnoses, is just too long..” DS230058

A major interface issue of concern to the professional staff participating in the focus groups was that of hospital discharge. Efforts had been made to improve discharge planning and in general this seemed to be bearing fruit:

“Everyone leaves the ward with a discharge plan and a copy of that will be with the carer and the client themselves.” DS230058

However, there was great concern expressed about care of patients with dementia in general hospitals. Not only there was there insufficient dementia awareness of general hospital staff but the concerns expressed echoed those of carers who were willing to provide more individual support but this was prevented by hospital routine:

“I think they focus primarily on the physical / medical status and do not take into consideration the actual cognitive functioning and how that affects the medical status ..., it can be very, very difficult...” DS230057

“nobody had the time to encourage that person to eat or if they need feeding, and things like taking fluids, although they have been involved with somebody who was diagnosed with being dehydrated, was alright when they went in hospital..” DS230057

“a lot of the wards are very strict on times, and a lot of carers would be quite happy to go in and help get the person they care for dressed in the mornings, sit with them at mealtimes, carers to go to the ward-round so that they can get the information and they are not allowed to. There is free help there and they are not allowing it...” DS230057

Communication and information transfer between professional groups had been a subject of investment in government initiatives in assessment and record keeping systems, and promotion of the use of inter-agency compatible information technology. Nonetheless, there remained marked problems about information transfer across hospital/community and social care/health care boundaries:

“Where we have serious incidents it is sometimes around that interface and how we get information to go back and forward, because we don’t all have the same systems in terms of electronic systems for reporting, we have completely different sets of notes and none of that information is shared.” DS230058

Hence it was clear that despite much policy development, mechanisms for smooth information transfer between different parts of the NHS and between the NHS and social care were found to be lacking. Clearly this could impede the implementation of an integrated care plan.

A final theme in relation to communication was shaped by differing understandings of the importance of confidentiality, especially amongst staff in general hospitals not trained in dementia care. Sometimes important information would be provided to the person with dementia but not to their family carer, for reasons of confidentiality, with the consequence that this information could be lost and not acted upon:

It is information providing as well., communication and because of data-protection and confidentiality they don’t always., they give the instructions to the patient, the person with dementia, but the relative needs to be saying, “you need to be telling me as well”, and they say, –“oh no, no...” DS230057

Clearly lack of attention as to who should appropriately be involved in communication this could have negative consequences for the physical health care of a person with dementia.

Participants description of the information and communication over the trajectory of dementia

Although communication at different stages of dementia will tend to be with different parties, a common theme raised by staff at all stages of the care process was that of focusing upon effective communication with carers, helping them to understand the process and to improve communication between carer and the pwd.

“..a lot of the care that you give, a lot of the interventions that you deliver are to the carer, not necessarily to the person, and that is about providing education, helping people to look at a different way of managing things, for themselves and for the person [with dementia].” DS230058

“One of the things that we do is to run a group for the person [with dementia] and the carer together, and we have been ...using reminiscence life-story type work and that has been about facilitating communication in different ways and allowing people still to see the person rather than to see the disease..” DS230058

This investment in improving communication between carer and cared-for was seen as important in supporting the caring relationship.

Participants description of the information and communication depending on if care is provided at home or in a nursing home

Professional staff raised concern about the variability of quality in nursing and residential homes where communication between staff and residents was limited:

“.. the social side of everything just comes to a stop, because you are in there... Unless you want to watch telly, or play bingo, or watch Jeremy Kyle, or listen to the radio.., you know, that is what it is like..” DS230058

Participants description of collaboration from and between professionals

Unlike the mixed picture painted by carers, there was generally a view from professional staff that communication and collaboration with general practitioners was improving.

“..working with the GPs, we have really seen an improvement. We have badgered them that long and that hard, for the information that we need. There still is only one or two GPs who will send a referral that will say, - ‘Dear Team, please can you see this 87 year old confused person, Thank you’.., and that was the quality of the referral, whereas now...we now get all the blood results, sometimes an ECG, if they have got a CT scan on file, that will come with them, a list of medication, medical history, [we] work really hard with GPs, that has obviously filtered through..” DS230058

“We no longer get any referrals saying ‘this person needs residential care’, we don’t get that any more..” DS230057

It appeared that efforts to improve working processes between the Community Mental Health Teams for Older People and GPs through joint meetings, outreach workers and liaison staff had begun to change ways of working and improve collaboration.

Collaborative working with the general hospitals was being undertaken to address some of the problems of communication and poor quality of care. In order to improve dementia care on general hospital in-patient wards, the mental health service (a separate NHS Trust) was providing a psychiatric liaison service to address some of the quality of care problems:

“one of our support worker posts on the liaison team actually works and directly provides care to people in the general hospital, so will feed people, will make sure that they take their medication, they will actually deliver that care.” DS230058

This piece of collaboration appeared to be influencing quality of care.

Separate operational procedures and norms were found to make for real difficulties for health and social care in providing an integrated service. The Social Services had established defined procedures to ensure that publicly funded nursing and residential home places were only available when community based care was no longer viable. However, this did not mesh with the working of the Community Mental Health Service who had already tried intensive home support and failed. The consequence of such control procedures was that staff would often use emergency processes to circumvent them.

“I went to a lady recently to do an assessment, she needs to go into care...things were so risky at home.... and her need, her risks were such an extreme step..., so I called social services and had a meeting and a social worker said ‘we can't put her into care, my manager has said we need to do this, this, and this first, so no matter what the risk is, no matter what the situation, the answer is, and it is a manager who can't see in social services instructing that social worker, saying.., ‘no.., before you do anything, or put her in 24 hour care, you will have to try and extend the package of care’, and I am saying no.., sorry.., this person could fall back down stairs, they have got rails, but.. they can hardly walk, downstairs living is out, we have tried that, it is not working, it's really risky, but getting round that is very difficult, because there is a faceless social services manager who is not actually looking at the case, saying, ‘no you have to try this first for financial reasons’, and you are thinking the only desperate way to get around it was by saying.., well emergency respite..” DS230058

Participants description of the collaboration from and between professionals over the trajectory of dementia

The perception of the professional staff was that there was necessarily a marked difference in the level of support available in the late stage of dementia compared with the early stage. In the early stage the main care was recognition by the GP, referral to a memory clinic for diagnosis and advice and review with medication. In the later stage more intensive home support, mental health care and related services are required and the greater level of provision is at this point:

“I am not sure there is a lot of early stage stuff.., you can get diagnosed.., we are a secondary mental health service, the Primary Care Trust should be picking up stuff but they haven't got the money for it either. So the early diagnoses people are just being [told], ‘well you've got Alzheimer's or some other form of dementia.., just go away and come back in six months time and we will see how it is’. There is nothing out there for them.” DS230058

“.. the resource that we (specialist mental health services) have got is finite but the demand is increasing so what we tend to do is to meet the crisis, because that fits better with secondary care definition and I think it is probably at the cost to the front end stuff, and I think we’ll pay the price for that later” DS230058

Participants description of the collaboration from and between professionals depending on if care is provided at home or in a nursing home

Quality of care was variable in terms of the lack of activity and stimulation in care homes and there were concerns about their capacity to deal with many of the behavioural problems of dementia. However, an outreach service to train and support staff in homes, linked to the community mental health team for older people was proving to be useful in preventing unnecessary admissions to hospital from homes. This level of service was only provided to support residents in homes.

Particular concerns were expressed about the need for more individualized and personalised care at home and in particular for more specialized forms of home care to meet the needs of people with dementia:

“.. home care at present you get four visits a day maximum, usually the service user has to fit in with the care agency and I would like it the other way round.” DS230057

“We are still coming across issues, where some care agencies...are going four visits a day, [to] a person with dementia and they go in and say, - ‘I have come to do your breakfast’ and they say, - ‘oh I have had my breakfast love, I don’t need any breakfast’, so the home care trot off and you go around two weeks later and think.., My God.., you know.., how long has this person.., so it is trying to educate the current home care service - don’t take it as read that they have eaten. It doesn’t matter if they have, still leave food. If they have eaten, it doesn’t matter.” DS230057

In this latter case it is the need for training in support of older people with dementia that is seen to be required. The person describing the circumstances, a specialist mental health team worker, is referring to the lack of recognition of the impact of cognitive impairment by non-trained home care staff.

Participants overall reflection of care at its best versus not at its best

A number of examples of good practice and ways in which care can be improved were cited by participants. A number of these are noted above, including improving links between specialist mental health services and general hospitals, but in addition several key points were identifiable. Firstly there was the importance of ensuring that residential and nursing homes did not become ‘islands of the old’ but were linked with mainstream services. The specialist outreach team from the mental health service offered support to care homes through advice, training and individual consultations about patients:

“I think because we have got a nice residential home team and also because our HIT team are quite a lot in the home, it is not just the training...the fact is that if everybody knows what that training consists of, then you can go out and you can follow them up on that..” DS230058

It was noted that the presence of this specialist team was developing the skills and competencies of the nursing home staff:

".. quite a lot of nursing homes have done a lot of work.. they will ring up and say, - 'can you come and see such a body....they are behaving in such a manner, we have already dipped their urine, we have already asked the GP to check their blood..'.. so some of that message gets through as well..." DS230058

Secondly, the management of prescribing in a number of residential and nursing homes by specialist mental health services was also seen to have led to benefits compared with GP led prescribing:

"That was because the GPs were over-prescribing, and therefore they were knocking people out, whereas the psychiatrists are much more skilled at the correct doses and what to use.., the mistake with GPs over-sedating people has left this kind of impression that it is just completely wrong.., when in fact it is not and it can be very useful in certain situations.." DS230058

Synthesis

A number of features emerge through the focus groups indicative of potential good practice in dementia care. There are five factors which seemed of particular salience.

- First, primarily emerging from older people and their carers was the theme of the initial contact with primary care and general practitioners. A clear need was evident to improve awareness of dementia which had been experienced as extremely variable in order to facilitate early diagnosis and access to support. However, the relationships with primary health care were described as much more positive by specialist mental health services. Suggesting that some of the links between primary and secondary care were improving.
- A second key theme was the improvement of the quality of care of older people with dementia in acute hospitals. Training was seen as an important vehicle to achieve this which emerged as a concern of both older people and their carers and professional staff.
- A third theme for carers of people with dementia was the need for readily accessible breaks and respite in a predictable place where the person with dementia was comfortable and the carer felt secure in the knowledge of this.
- A fourth theme was that of a single point of access to care and support and associated with this more integration of the services needed for dementia care. The need to bridge the health and social care divide more effectively was frequently noted, although problems with other boundaries were also apparent (acute/mental health care; primary/secondary care). As part of this theme, the effects of different agencies pursuing related goals but in different ways, a consequence of different funding streams and tightly defined targets, was seen as having a negative effect upon the delivery of person centred care.

- The fifth theme was the need for services to be more flexible and creative, whether they were hospital based or community based. Again this related the need for individualization of services to fit the very different circumstances of people with dementia.

It is noteworthy that the majority of these are themes well identified both in policy documents and the literature.

REFERENCES

Stevens, P.E (1996) Focus Groups: Collecting Aggregate-Level data to Understand Community Health Phenomena, *Public Health Nursing*, 13, 3, 170-176.

