

Obstacles to Shared Care for Patients with Dementia: A qualitative study

Steve Iliffe, Jane Wilcock and Deborah Haworth

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Background. All Primary Care Trusts in England were meant to have shared care protocols for antedementia medication use in place by 1 April 2004. Shared care of medical treatment in dementia depends upon early diagnosis, but under-recognition of and under-response to dementia appear widespread in general practice.

Aim. To investigate the perceptions of specialists and generalists about the potential for shared care of people with dementia.

Design of study. Qualitative study with semistructured interviews.

Setting. Three inner-city and two rural areas.

Methods. Semistructured interviews were arranged at the participants' convenience and were tape-recorded and transcribed. Thematic analysis of the anonymized transcripts was undertaken and a case and cross-case analysis was performed.

Results. Thirty-nine GPs and 30 specialists were interviewed. Broad themes were reduced to following four key categories which appear to be layered over each other: therapeutic nihilism; risk reduction or avoidance; concerns about competency; and resources for shared care.

Conclusion. Roles for primary and secondary care professionals are inappropriately distributed and require clearer definition. Resistance to shared care mostly comes from within general practice and reflects concerns about staffing, time constraints, lack of experience and confidence in making and disclosing a diagnosis. Developers of shared care protocols must dissect layered obstacles, addressing the issues of therapeutic nihilism, risk management and clinical competence.

Keywords. Dementia, primary care, qualitative research, shared care.

Background

Early recognition of dementia is rising up the global policy agenda, driven in part by the emergence of a new generation of antedementia drugs, but the implications for health and social care services have not been explored sufficiently.¹ Nevertheless, the National Service Framework (NSF) for Older People (2001) detailed new national standards of care for older people, including those with mental health problems. Standard seven of this NSF states that older people who have mental health problems should have access to integrated mental health services, provided jointly by the National Health Service and local government, to ensure effective diagnosis, treatment and support for them and their carers. By April 2004, Primary

Care Trusts should have ensured that shared care protocols had been agreed with local specialist services, to diagnose, treat and care for people with dementia (DOH, 2001).²

Shared care, defined as shared responsibility, enhanced information exchange, continuing medical education, and explicit clinical guidelines between a hospital outpatient clinic and primary care, appears a rationale division of labour within medical systems dealing with long-term medical problems. There is evidence of benefit in the management of diabetes,^{3,4} heart disease⁵ and urinary tract disorders.⁶ Although we could not find examples of rigorous evaluation of shared care in neurodegenerative disorders (like dementia syndromes), there is some evidence about the impact of shared care approaches from the

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Centre for Ageing Population Studies, Department of Primary Care & Population Sciences, Royal Free & UCL Medical School, UK. Correspondence to Dr Steve Iliffe, Centre for Ageing Population Studies, Department of Primary Care & Population Sciences, RFUCLMS, Royal Free Campus, Rowland Hill Street, London NW3 2PF, UK; Email s.iliffe@pcps.ucl.ac.uk

management of long-term mental health disorders which may be relevant to dementia care. For example, a Canadian study developed a monitoring programme between psychiatrists and primary care practitioners which aimed to provide GPs with support for patient management by facilitating improvements in communication. Evaluation through case notes and a satisfaction and effectiveness questionnaire found improvements in satisfaction and care with improved access to specialist support.⁷

McCrone *et al.*⁸ examined the economic implications of differing levels of shared care for people with enduring mental health problems. A multivariate analysis of case histories found participants receiving a low level of shared care used residential care services less and had fewer contact with secondary care specialists, with associated lower costs compared with those receiving medium or high levels of shared care. The impact of the differing levels of shared care and the differing patterns of service use were not linked to health outcomes.⁸

An exploratory cluster randomized controlled trial of people with long-term mental illness evaluated a mental health link programme which aimed to improve communication and care between specialist teams and primary care. Intervention patients had fewer relapses but with no differences in documented patterns of care compared with control group patients. Intervention practitioners were more satisfied and improvements in service development were noted. There was an increased mean cost of £63 for patients in the intervention group (2004).⁹

If this evidence is applicable to dementia syndromes, shared care for people with dementia, as required in the UK by the National Service Framework for Older People, can be defended as being likely to improve the experience of care for all parties, although possibly at greater cost to the services.

Rationalization of dementia services seems realistic given both rising public awareness of possible cognitive, emotional and functional changes, and increasing vigilance among community-based professionals.¹⁰ However, there remains a problem of under-recognition and under-response to dementia in primary care.^{11,12} This under-recognition and under-response may be due in part to the failure to recognize signs of a complex and slowly evolving disorder, and in part to negative attitudes towards the diagnosis and assessment of dementia.¹³ GPs may be embarrassed or anxious about carrying out cognitive function tests,¹⁴ and do not benefit from using standard diagnostic criteria presented as clinical guidelines.¹⁵ Practitioners who have most difficulty in making the diagnosis of dementia also have more problems in disclosing the diagnosis, particularly to the person with dementia.¹⁶ Nevertheless, GPs are being encouraged to undertake activities that they find particularly difficult, but are

urgently needed,¹⁷ like providing education, offering psychological support for carers and mobilizing carer social support.¹⁸

There is a danger that policy will run too far ahead of practice, and be dismissed as unrealistic. The policy imperatives promoting collaborative working across disciplines for people with dementia, and the problems of diagnosis, management and support for individuals and their families prompts a question for general practice: what are the necessary and sufficient conditions for shared care of patients with dementia? In this paper we describe a qualitative study that explores this question from the perspectives of generalists and specialists involved in dementia care. In it we make the assumption that shared care refers to clinical care divided between generalists (doctors or nurses) and specialists [doctors, nurses or psychologists working in old age psychiatry, medicine for the elderly, community mental health teams (CMHTs), memory clinics or neurology].

Participants and methods

We interviewed specialists and GPs in purposively selected urban and rural settings to discuss dementia diagnosis and management, and attitudes towards shared care of patients with dementia. Sites were selected to reflect the different populations of inner city, urban, suburban and rural areas. One area in Scotland was included (even though the National Service Framework for Older People does not apply there) because there was a long tradition of collaboration between a pioneering Dementia Care Centre at Stirling University and local general practices. Specialists included old age psychiatrists, community mental health nurses and psychologists, but we did not include primary care nurses because on the basis of other work^{19,20} we felt that their involvement in the development and early implementation phase of shared care protocols was likely to be limited. Approval was obtained from ethics committees in Camden & Islington, Barnet, Bradford, North Cumbria and Forth Valley. Interviews took place between April and December 2003, that is after the publication of the National Service Framework for Older People but not the deadline for the establishment of shared care protocols for dementia of 1 April 2004.

Semistructured interview schedules were developed from a review of the current literature, piloted with GPs before the study started, and amended for the main study. The themes covered in the interviews are shown in Table 1 and are designed to elicit views and experiences from GPs. The same questions were asked to specialists, but the discussion about shared care was opened with the question: *Would you consider requesting shared care of patients with dementia with colleagues in general practice—for example, in monitoring the effects of anti-dementia drugs?*

Two experienced female qualitative researchers with a background in ageing-related research conducted the interviews [JW, DH].

All GPs and specialists in the care of older people with dementia were invited for interview by letter. Interviews were arranged at the participants' convenience and were tape-recorded in the practitioners' workplace with an assurance of confidentiality and anonymity. The tape-recorded interviews were transcribed. Thematic analysis of the transcripts was carried out in which the text was coded and annotated to identify emergent regularities in the text and grouped into themes.²¹ The codes and annotations from individual interviews were pulled together and patterns and regularities across the data were then sought,²² that is, case analysis was followed by cross-case analysis²³

[SI, JW, DH]. For each individual case, we compared the attitudes and experiences of each clinician towards dementia diagnosis and management and shared care. We also compared the decision making process and other themes emerging from the interviews across the two professional groups.²⁴ Data analysis was commenced during data collection²⁵ and as subsequent interview data were analysed, themes were added to and altered. When it appeared that themes had been validated by sufficient interview data, that is, when the data had reached theoretical saturation, recruitment efforts and interviewing were stopped. To ensure reliability, the original transcripts were read and the themes agreed by all authors.

Results

GPs

We approached 114 GPs and 39 (34%) were interviewed. Fourteen GPs were located in the London area, 5 in Bradford, 11 in Cumbria and 9 in Central Scotland.

Specialists

We invited 53 specialists in the same localities and 30 (57%) agreed to be interviewed. Sixteen old age psychiatrists, four Clinical Psychologists, one counselling psychologist, five Community Mental Health nurses, three Admiral Nurses and one Clinical Nurse specialist agreed to be interviewed. Twenty-five specialists were located in the London area, none in Bradford, four in Cumbria and one in Central Scotland.

The characteristics of the interview sample are shown in Table 2 below.

The themes have emerged from the initial analysis of transcripts, and the broader categories into which we grouped them are shown in Figure 1.

We reduced the themes to the following four categories: therapeutic nihilism; risk reduction or avoidance; concerns about competency; and resources and

TABLE 1 *Interview guides*

| Semistructured interview schedule for GPs | |
|---|--|
| I would like to ask you some questions about your experience of recognizing and responding to dementia in general practice (and working with colleagues in general practice) | |
| Why is dementia sometimes difficult to diagnose early? | |
| Are there situations when an early diagnosis might cause more problems than it solves? | |
| Why can it be difficult to talk to patients about the possibility of dementia? | |
| What is the 'average citizen's' perception of dementia, and how accurate is it? | |
| How easy is it for you to judge the severity or stage of dementia? | |
| If your local Old Age Psychiatrist, geriatrician or neurologist asked you to undertake shared care of patients with dementia—for example, in monitoring the effects of antidementia drugs | |
| What would be the advantages? | |
| How would you overcome anticipated difficulties? | |
| What would you see to be your role/responsibilities? | |
| What would you see to be the consultants' (GPs') role/responsibilities? | |

TABLE 2 *The characteristics of the interview sample*

| Profession | Age | Gender | Year qualified | Ethnicity | Category | No of interviews |
|------------|--|------------------------------------|-------------------------------------|--|-------------------|------------------|
| GP | 47 years (<i>N</i> = 31), range 31–62 years | Male 19 (<i>N</i> = 39, 49%) | Range 1966–1995 (<i>N</i> = 31) | Indian 3 (<i>N</i> = 39, 8%) | Urban GP | 24 |
| | | Female 20 (<i>N</i> = 39, 51%) | | White 36 (<i>N</i> = 39, 92%) | Rural GP | 15 |
| | | | | | GP Total | 39 |
| Specialist | 43 years (<i>N</i> = 24), range 31–65 years. | Male 13 (<i>N</i> = 30, 43%) | Range 1962–1998 (<i>N</i> = 23) | Black-African 3 (<i>N</i> = 30, 10%) | Urban Specialist | 29 |
| | | | | Indian 3 (<i>N</i> = 30, 10%) | Rural Specialist | 1 |
| | | Female 17 (<i>N</i> = 30, 57%) | | White 24 (<i>N</i> = 30, 80%) | Specialists Total | 30 |

roles. No differences were discernible between respondents in England and in Scotland in the content and meaning of these themes. In the boxes containing quotes, S and GP refer to specialist and generalist.

Therapeutic nihilism

There are genuine difficulties in recognizing dementia in its early phases, in distinguishing it from other clinical disorders like anxiety states and depression, in monitoring changes in dementia (particularly when ACEI medication is being used) and in understanding some of the problems that emerge in the course of the disease process. Specialists do not believe that GPs lack competence to undertake these tasks, but rather lack either specific skills (which could be acquired) or, more

seriously, lacked a general commitment to undertake the tasks of dementia diagnosis and management; that is, they identified a problem of therapeutic nihilism (see Box 1, quote 1).

Therapeutic nihilism is associated with images of dementia as a severe disability and with the stigma of mental illness (a literal loss of mind) held more broadly in the population (see Box 1, quote 2).

These forms of negativity not only hold back recognition of early dementia, but can influence professional awareness of the services and resources available to people with dementia (see Box 1, quote 3). As a consequence of the negativity surrounding the diagnosis of dementia some GPs may delay referral to specialist services, feeling that the tests required are intrusive and potentially frightening to the person and families involved (see Box 1, quote 4). Specialists noted this delay in referral and also the variability in the quality of information given at referral (see Box 1, quote 5).

Risks reduction or avoidance

There are serious dilemmas for professionals in making and disclosing a diagnosis of dementia, arising from anxieties about the impact of disclosure and the coping strategies that individuals use to come to terms with a progressive disability (see Box 2, quote 1). A view expressed by some old age psychiatrists was that the risks of early diagnosis of dementia, and therefore of early

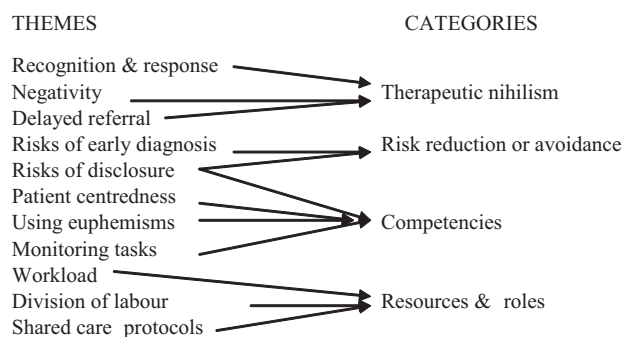


FIGURE 1 Emergent themes and categories

| Box 1 <i>Therapeutic nihilism</i> | |
|-----------------------------------|---|
| Recognition and response | 1 ... In my experience the failure of some GPs to take the complaints that the family come with, seriously. Things like, I mean, people do still say 'its part of getting old, don't worry about it' or ehm, or even 'this might be dementia but there's nothing we can do about it'. Both of these are manifestly wrong. S56, Psychogeriatrician |
| Negativity | 2 GPs are starting to realise that seeing people earlier is a good thing. That actually people can do something about it. At the very least to get the sort of services in train and also to introduce the idea of the cholinesterase inhibitors. But there's still a lot of people who don't feel that there's much one can do about dementia. So you know, probably best to not even think about it too much until the problems start occurring. So I think that attitudes still around with some GPs. S2, Psychogeriatrician |
| Delayed referral | 3 And then there is a delay ehm in referral, an ignorance perhaps of what can be achieved and what services. ... We did an audit, again this was strictly only local, but we did an audit of local GPs about two years ago. And one of the things we were asking was 'do you know how to make a referral to our service?' and 'do you know what our service comprises?' In addition to asking whether people were satisfied with it. And it was amazing the lack of knowledge, you know obviously quite an expensive and extensive academically led service, there was lack of local knowledge about it. S56, Psychogeriatrician |
| | 4 So it can be quite traumatic putting somebody into that system, particularly with the availability of the new drugs and them [specialist] wanting a full package of assessment before they'll actually see them. You have to be very explicit about why you are suddenly doing, syphilis serology and chest X-rays and ECGs and things, and I think you have to try and be open but sometimes that can be quite difficult. GP17 |
| | 5 When we get the referrals to the team here we get varied referral letters, some are in very in depth detail and some are you know very sketchy. And then because of the sub consequent problems of following up the referral depending on how much information we get ... S55, CPN |

Box 2 *Risk reduction or avoidance*

| | |
|--|--|
| Risks of early diagnosis and risks of disclosure | 1 And you know its also about how do we manage our anxieties about saying to people and about how people will respond and I think that's how it connects with preparing people and who would be prepared to talk about it so that they're not just left with this information. |
| | S53, Clinical Psychologist |
| | 2 I think the benefits of diagnosing it early outweigh the, you know, the, any potential problems and the potential problems I think we just have to be aware of them and we have to do something about them. . . . Well the earlier you diagnose the better the person will understand the condition they have, they are in a better position to make plans about their future, and they want, you know, have business to sort out, relationships to sort out, things they might have wanted to do which they haven't done yet, you know, holidays they want to take, whatever, you know, for the individual. The other side also is there's the possibility of treatment and the earlier you treat it, I personally believe, the better, the greater the benefit for the individual. |
| | S5, Psychogeriatrician |
| | 3 I suppose I would also be cautious about being sure of a diagnosis especially without thinking about the impact it can have on how people are treated and what options people feel are open to them. |
| | S53, Clinical Psychologist |
| Patient centredness | 4 I think often making diagnosis can cause more problems than they solve, often in conditions where there isn't an obvious. . . . cure. So if you've got a condition that is a chronic condition that will deteriorate and you have no intervention that you can offer. And the patient is functioning perfectly well, within limits, but they are managing, they are not a risk to themselves, they are not a risk to the public, ehm . . . then I'm not sure what can be gained by telling them that they have a chronic condition that is going to lead to them losing their ability to function completely, to my mind that might precipitate a condition, like co-existent depression in someone who is otherwise perfectly happy dealing with, you know, their 'slight memory loss', and it's 'just old age' and you know. |
| | GP45 |
| | 5 As a CPN we tend to use more friendly terminology like ehm, 'difficulties you're having with remembering things', and 'managing', and again going back to the care package. Relating it to the care package. 'You're having trouble managing', and people vary, vary so much with the dementia as to how far the dementias progressed, as it very often is somebody whose got no insight, or practically any insight into what's going on and, I am slow to use that word 'insight', you know what I mean? Most of my experience lately is with people who don't have that, again in inverted commas 'insight' and therefore it's, I suppose in a way it's easier to talk to them on a level, in a way that they 'just can't manage things generally'. |
| | S55, CPN |

disclosure, are few and were easily offset by a well-organized system of support to people with dementia and their families (see Box 2, quote 2). This view seemed to emerge in places with well coordinated multidisciplinary teams. Other views from centres with different approaches were less positive (see Box 2, quote 3).

The exception to this 'low risk' view arises when people with early dementia have an image of its end-stage forms that does not correspond to their experience of changes in themselves. In this circumstance there is potential for a depressive response and disengagement from services (see Box 2, quote 4). The processes of diagnosis and disclosure therefore need to be tailored to the individual, which is where knowledge of the individual before the onset of changes becomes vital.

The need to be person-centred is stressed when professionals are anxious about making and conveying the diagnosis of dementia, and results in the widespread use of euphemisms ('memory problems') or in reframing the primary need as one for support and care rather than for the naming of the disease process producing changes (see Box 2, quote 5).

Competence

A significant proportion of GPs believe that the clinical care of dementia is a specialist task, and are reluctant to participate in shared care. They have particular anxieties about misdiagnosis and its implications for patients and the doctor-patient relationship (see Box 3, quote 1).

Although specialists always advocated conveying the diagnosis to the person and families involved they also acknowledged that talking about dementia was universally difficult, particularly when the patient lacked insight (see Box 3, quote 2).

GPs are aware of the specifics of monitoring that will be required of them in shared care of dementia, but felt that this was not where their area of expertise lay, seeing their role more as an overview of the individuals situation and physical health issues. Stopping medication was viewed as difficult by GPs because this would affect the relationship with their patient. Specialists who were viewed as external to this relationship were seen as better placed to be objective and to take on this uncomfortable role. Problems arising with polypharmacy were also seen as a barrier to medication management by some GPs (see Box 3, quote 3).

Box 3 *Concerns about competency*

- | | | |
|----------------------------------|---|---|
| Risks of disclosure [experience] | 1 | I think with any new drug, I think there is the experience thing, you know, I may have perhaps one or two patients a year who perhaps benefit from this drug, and therefore I'm not going to have the clinical the experience to say 'well, yes I think this the right situation, right drug in this situation'. Whereas I think if you if you're a consultant psychogeriatrician perhaps seeing twenty or thirty people a week you'll be much more able to say, on balance 'I think this person would benefit or not benefit'. GP17 |
| | 2 | Only in that if the person still has insight it could affect them badly. And people get very depressed if they think they have got Alzheimer's. That can cause, and I can think of a very close friend of mine who was a clinical psychologist who was fully aware of dementia, and she didn't want to know. I recognised it very very early on and I pointed it out and she didn't want to know. It's, it's a denial, it's a worry. Also the families concerned because they think it's genetic and 'will I get it?' so denial really. S8, Psychogeriatrician |
| Monitoring tasks | 3 | So there is a kind of overview role and I think particularly around drugs, you know these patients are often on really substantial poly-pharmacy, and individually you can see that you know ok well we should be doing this stuff for secondary prevention of their heart disease but if it's four drugs for that and then three drugs for the hypertension, something for the diabetes and then you add in their anti-dementia drugs you start to say 'is it really in an individuals best interest?' GP17 |
| | 4 | I mean I think from the GPs perspective one of the most difficult things they have to face are people with moderate to severe dementia who develop behavioural difficulties. Now these are, I think this is another domain for using the specialist service, another reason for accessing us. And that causes an immense amount of strain amongst carers, its difficult to manage pharmacologically, you sometimes have to admit people, people have to go into continuing care. So and people need very regular follow ups. So if you've got a good relationship with the GP that can again work extremely well. I think people are contained better and probably stay longer in the community. S56, Psychogeriatrician |

Box 4 *Resources*

- | | | |
|------------------------------|---|---|
| Division of labour and roles | 1 | Ehm, the consultant geria, psycho geriatricians also have ehm, a much easier way of leading the team it seems to me. You know they've got their CPN and they have a sort of direct line to the social services support and because it's what they're doing all the day, you know, they have a checklist in their head. Whereas we tend to do it in bits and pieces so were more likely to miss something out. GP46 |
| | 2 | Our role should be like establishing the diagnosis or confirming the diagnosis of dementia and to really co-ordinate the support services because we are closely attached to the social services and the community team. So to plan or formulate, to formulate a plan for the future care, even when they are progressing through different stages. S44, Psychogeriatrician |
| | 3 | Well obviously the reluctance to refer is the cost. And not because we would personally be liable for the cost, we would rate these drugs as high cost drugs and so they're outside the budget fro the GP, so there's that point of view, but there's the overall cost for the health service as it were and you've got to say to yourself, 'is this affordable?' GP72 |
| Workload | 4 | I think the monitoring are well within the limits of . . . the expertise of the GPs, certainly, absolutely. But ehm, I just think it's too time consuming for them. I think they would find that difficult. S2, Psychogeriatrician |

GPs and specialists both acknowledged that specific problematic cases would be within the specialist domain particularly with behavioural problems (see Box 3, quote 4).

Resources

The diagnostic decision-making process in general practice is influenced by perceptions of the availability and accessibility of specialized support for the person

with dementia. GPs viewed specialists as being gatekeepers to acute mental health services such as specialist wards and Community Psychiatric Nurses (see Box 4, quote 1). Specialists mirrored this view in their role coordinating support services with their close working with the community mental health teams (see Box 4, quote 2).

The cost implications of prescribing and monitoring medications were also frequently mentioned by GPs

Box 5 Roles

- 1 And then I think its fairly clear the medical needs, cause often these are elderly patients who will have co-morbidity . . . and I think most GPs understand that those won't be taken on by the psychiatrists and we would do that anyway, but I suppose that's part of the overall picture. So what does that leave really; those patients in the small numbers who are on dementia drugs and being clear about who's prescribing them, monitoring them, changing doses, changing agents or whatever? and I think because they're fairly new and quite specialised at my practice certainly we've kind of left that to the specialists but as they become more mainstream then I'm sure we would be happy to look after those sort of drugs. GP18
- 2 I think the GPs has to be, I think their responsibility is to be open and accessible, which is again it's a difficulty with the number of people that they have to see . . . but I think the role has to be, greater skill in identifying the problems, using the specialist services that are there, but also accepting that the specialist services can't maintain our responsibility forever and will refer back at some point, but being able to kind of refer. I think they're very, they're key GPs
S78, Admiral Nurse
- 3 I mean shared care I think is very much the way we should be moving. It's about creating a comfortable working relationship between specialists and general practitioners, so there's trust and confidence, that if I'm out of my depth you'll take the patient on. And if this patient isn't appropriate for me you'll take the patient back. There's something about the, very much, the comfortable interface that allows patients to move backwards and forwards very smoothly without anybody resisting the move. I suppose that's around identifying patient pathways and being very clear about the role of each person in that pathway in managing the patient. But the patient shouldn't be aware of that, it should all feel very smooth.
GP45
- 4 I regard secondary care as being the servant of the GP and we are there to provide help support and expertise when they want it. And when there's a mutual respect for each others status and ability, and this flat sort of egalitarian approach, then things work very well. So under those circumstances there's great shared care. A GP will refer to me a patient and my view is that it's then my responsibility to see, assess, investigate, diagnose and initiate a management plan . . . my idea of shared care is clinicians from different geographical sites, or different disciplines, primary care or psychiatry, moving, working together to create a watertight model of care for a patient, however that is. However that's set up. It varies with the GPs.
S16, Psychogeriatrician
- 5 Individual GPs refer quite a lot and some, as far as I can see do almost everything and some do remarkably little for my patient group, and probably the ones that are doing less for my patient group are doing more for another patient group, and GPs have individual interests. So I think that a lot of it is to be responsive to the individual GPs and I think it's helpful to make the overall . . . the first diagnosis and to talk to the family about it, because if I do that sort of thing a lot I'm obviously just going to have a lot more resources and a lot more of it in my head that other people.
S4, Psychogeriatrician
- 6 Yeah, from the diagnosis point of view, from the initial assessment a dementia screen ehm, there's definitely more room for consistent toing and froing of information because some GPs, some surgeries will do dementia screening automatically and they communicate that in some form, ehm, yeah specifically for the anti-dementia drugs there's been some problems recently around, over the last couple of years about, at what point do GPs take over the prescribing and I'm sure that wouldn't be such an issue of again we had more of a communication between us. But it seems to have come up in just a few practices.
S55, CPN

(see Box 4, quote 3). In order to deliver shared care GPs felt that protected time and additional staff would be required. Specialists agreed with this feeling that GPs could manage well with monitoring medications but that shortage of time and resources would have an impact upon this (see Box 4, quote 4).

Roles

Specialists tended to see the usefulness of the GPs role as dealing with co-existing physical problems and in their close relationship with the patient in the community. GPs did acknowledge that treating other physical problems may be a more pressing need than providing dementia care within the normal consultation process (see Box 5, quotes 1–2).

Shared care was viewed as possible within the restrictions of time, resources and definition of roles (see Box 5, quote 3). Most GPs considered shared care

existed to an extent already, although working together and good communication appeared to be built at an individual rather than organizational level (see Box 5, quote 4).

Specialists described shared care with general practice positively; however, they did not see it as key to the highly supportive system needed at the time of diagnosis and its disclosure (see Box 5, quote 5). There was one exception (a GP whose MD thesis was on shared care, see Box 5, quote 3). Specialists also thought there was a need for clarity on definition of roles (see Box 5, quote 6).

Discussion

Shared care of patients with dementia already exists, where long-standing relationships between specialists

and selected GPs allow easy communication. However, we believe that the narrow focus in the discussion of risk avoidance on the hazards of diagnosis is evidence that GPs were not familiar with management of dementia in the community, even though shared care was seen as happening, even if only informally. In our view their responses reveal significant obstacles to the extension of shared care approaches for people with dementia that need to be articulated and acknowledged before they can be overcome.

Our reading of the data from our interviews is that the core issue for practitioners is resources, meaning the availability of personnel and time to respond to patients with dementia. The message that emerges is that shared care programmes are unlikely to thrive in the absence of engaged and collaborative specialists, with the necessary level of support from community mental health nurses and psychologists. We do not get the impression from the accounts that this judgement arises from experience of shared care, but is an untested presumption, contradicted by those who seem simply to be getting on with it.

Around this core lies the issue of competence, in distinguishing the early changes of dementia from other disorders of later life, or in communicating the news about the diagnosis, or in reacting to problems that emerge in the course of the disease process. As Forget me Not (2000, 2002)^{26,27} and Renshaw *et al.*²⁸ demonstrated in surveys of GPs views on dementia, those working in areas where local training and education had taken place were more positive about the benefits of an early diagnosis. Educational tools and resources would be of benefit to general practice in reinforcing the benefits of initiating an early care package with multidisciplinary support, with specialists acting as both resources themselves, and as catalysts for changes in the division of labour. Making shared care protocols available may go some way to tackling therapeutic nihilism, and the anxieties about risks and competencies expressed by professionals, by widening discussion about the tasks of dementia care and the roles that different disciplines can play.

These are complex issues, as shown by the widespread use of euphemisms, which are explicitly linked to professional anxieties and difficulties, but also to an awareness of different coping strategies in different individuals. Practitioners talk indirectly or overtly about the need to minimize risks in reaching, conveying and responding to a diagnosis of dementia, and this risk awareness is the layer surrounding concerns about competence. The respondents demonstrated how they try to develop highly tailored dialogues with people whom they know well. What may be seen as concealment of symptoms, and as professional collusion with denial on the part of the person with dementia or their family, can also be seen as a productive function of accommodation to the changes of dementia that has to be

understood and respected by professionals. Shared care projects that do not address this concern with risks may have problems in becoming embedded in everyday practice.

The positive experiences reported by some respondents have to be set against the opposite problem of therapeutic nihilism, the belief that interventions will not be beneficial, seems to be the most visible obstacle to shared care arrangements. This belief can find justification in some of the literature on shared care, which suggests that receipt of high levels of shared care is not necessarily associated with significant demographic or clinical characteristics and had limited value for patients in terms of improved clinical, social or general health functioning.²⁹ The NICE guidelines³⁰ are helpful in increasing awareness in primary care of the available pharmacological therapies, but the practitioners we interviewed were as sceptical about the benefits of drug treatment and inhibited in making early diagnoses by perceived limitations in local resources as those studied by Olafsdottir *et al.*³¹ This negative perception is unlikely to have softened with the publication in the *Lancet* of the limited effectiveness of long-term donepezil treatment for patients with Alzheimer's disease.³²

Nevertheless, the intellectual and humanitarian arguments for early recognition of dementia and systematic organization of care are powerful, leading to the conclusion that health services should strive to overcome the low status of dementia as a clinical condition, the limited skills and nihilism of professionals, and the collusion of families that act as barriers to earlier diagnosis.³³ Promoting shared care in dementia may reduce the nihilistic tendencies within general practice, simply by offering therapeutic interventions (both pharmacological and psychosocial) that can be used in common between generalists and specialists.

Limitations of the study: All qualitative analysis is a process of reduction and it is recognized that this can compromise the totality of the qualitative data.³⁴ We attempted to offset this bias by having the data analysed by three individuals from different disciplines, with an iterative approach to compare themes with text. We were not able to verify whether shared care protocols were ostensibly operational, or simply in development, and we are not always able to say consistently and with certainty whether respondents were speaking from experience, or in anticipation of shared care arrangements, except around the core issue of resources. However, there are some clear indications in some responses that *de facto* shared care arrangements were in place in some areas. Given both the extent of nihilistic thinking and the general underdevelopment of dementia care described in the background to this paper we believe it is reasonable to believe that shared care protocols were in the process of development, rather than reality, in most places. Those who participated in the study may not be representative of

their professions, but the similarities between our findings and those from another study comparing GPs from different urban and rural areas³⁵ suggests that our sample is not atypical. The limited representation obtained from professionals working in rural areas may mean that our findings do not necessarily apply to services in such areas. Our findings reflect the current realities of health policy and practice in England, and may not apply to different health care systems. However, the obstacles to recognition of and response to dementia are found across Europe, despite variation in systems, and we believe the main findings will be recognized by practitioners in other countries. The national significance is that the UK National Health Service is ahead of other services in promoting systematic multi-disciplinary management of dementia syndromes, across the primary/secondary care divide.

Conclusions

What are the necessary and sufficient conditions for shared care of patients with dementia? Those now seeking to create working shared care protocols for dementia syndromes will need to dissect layered obstacles if they wish to change clinical practice, first by demonstrating that something can be done to ameliorate the problems of dementia, then by putting risks into perspective, before addressing the complex issues of competence. The core issue is the availability of services that respond effectively to the needs of patients and professionals.

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